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**Understanding vaccination refusal: a qualitative study of
parents'
health beliefs and practices**

**By
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Abstract

Vaccinations and immunisations have become one of the cornerstones of health promotion and preventive health care globally and they are firmly embedded within the bio-medical model of medicine. That there have been objectors to mass vaccination programmes from the very beginnings of its history is often forgotten. Objectors are often characterised as dissenters, as irresponsible and implicated in the failure of public health policy to prevent epidemics by interfering with herd immunity protection of the population. This thesis aims to explore the reasons why some people actively choose not to vaccinate their children and to examine their health beliefs and practices.

Existing work with non-vaccinating parents has been dominated by quantitative and epidemiological studies attempting to determine why parents do not vaccinate or mixed method studies which also focus on lay perspectives; they aim to identify issues in order to help programmes to increase vaccination uptake. There is a shortage of studies focusing on the health beliefs of parents who make active decisions not to vaccinate in the context of those beliefs and health related practices.

This study focuses on a small group of parents who have consciously decided not to have their children vaccinated for the common childhood illnesses and extends to those parents where travel vaccinations were also refused. Fifteen adults were studied, one was not a parent; in depth open ended interviews were conducted. The research process highlights both the level of trust between researcher and respondent and the experience of feeling marginalised and misunderstood for their beliefs. Both influence the data generated.

The findings indicate that parents' experience with healthcare practitioners varied enormously; from support and encouragement for their stance on vaccination to accusations of being a 'bad parent'. In this study the respondents chose not to partake of the vaccination regime for their children because they believed that the vaccinations were either an unnecessary intervention, or, might do more harm than good. Some parents would never have any vaccination for themselves or their children in any circumstances as they did not agree with the principle at the outset. Others did not rule out all vaccinations in all circumstances, but kept an open mind. How people came to their points of view, who and what influenced them in their health beliefs and decision making varied and was complicated. Influences included the media, books, individual alternative health-care practitioners, parents, friends, the world wide web or some kind of 'gut feeling' that the practice was 'wrong', or a combination of some or all of these. There was no evidence for anti-vaccination pressure from any one organisation or person. Lack of faith, trust or belief in science as a health promoting body of knowledge was a significant aspect for some of the parents. Mistrust in the ethics of the pharmaceutical companies and their relationships with both the government and general practitioners made some of the parents mistrust their advice. Those parents who had a scientific background disagreed with the science of vaccinations.

The conclusion highlights the difficult position people who do not believe in vaccination find themselves in and the role of health beliefs that are embedded in different understandings of what constitutes health-illness and how health can be maintained.

DECLARATION

Except where specific reference is made to other sources, the work in this thesis is the original work of the author. It has not been submitted in whole or in part for any other degree.

.....

DEDICATION

This work is dedicated to my mother and father, Corrie Heirman-Kriegsman and Dr Leo J.R. Heirman. Their love, idealism and spirituality, their depth and breadth of knowledge and insight inspire me every day of my life.

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Introduction to the thesis

The background to the study

Having been a homeopath in Scotland with a busy family practice for many years, and having brought up my own six children, the topic of vaccinations has never been very far from the forefront of my mind. More and more frequently, pregnant patients or parents with young children make an appointment for what they like to call, “the homeopathic alternative to vaccination”. I then have to explain to these parents who have made considerable efforts to come to see me, and also pay for a consultation, that there is no such thing as an alternative vaccination. They are then disappointed as it would have been such an easy option to just have the homeopathic vaccinations instead. Long before the MMR debate, there were self determining people who chose against vaccination, but the debate itself was rather different then. It wasn't a fear of known damage from a particular vaccine that was stopping them vaccinating particularly, such as the fear of autism from MMR that we have now. It was more of a lifestyle issue then; certain groups of people just did not “do” vaccinations. The people who came for homeopathic treatment or for alternative vaccination advice frequently had a family history of alternative ways of keeping well. Some were from a background following on from the Reform movement; some had a family history of having a homeopathic family GP, or from an anthroposophical or a Steiner background. Others came from Holland, Germany, France or Northern Europe or India and South America where more diverse approaches to healthcare are more acceptable and homeopathy is better integrated. Often when I took a family history of a child from such a family, the parent would proffer, “Oh, and she hasn't had any

vaccinations!”, as if that were a matter of course in the world of related health beliefs and practices we both inhabit.

Over the years in my homeopathic practice in various setting and various places, I took a special interest in the non-vaccination attitude or stance. What was it that persuaded people to go so strongly against the flow of mainstream medicine, sometimes even to break or bend the law (in the USA and France) by not vaccinating their children? That was the question that led me to conduct this research. To be able to ask this question in an academic setting has been a great challenge. A large amount of thinking and writing from sociology had to be studied to facilitate a reflexive attitude to what is in many respects a taken for granted aspect of my practice as a homeopath.

Aims of the research

The overarching aim of the research is to explore the health beliefs and practices of parents who did not have their children vaccinated. Within that paradigm, to discover how and why people decided such, the health beliefs, whether implicit or expressed, underlying their decisions, what steps they took to keep their children well and how they dealt with the consequences of their decision.

The structure of the thesis

To begin with, in Chapter 1, the thesis reviews the practice of vaccination within the world of science and attempts to discover how the practice became such an integral part of western style (bio-medicine) medicine now promoted all over the world. That there have been people opposed to mass vaccination policies from the start, is discussed Chapter 2. This is followed by some of the sociological and anthropological viewpoints to the practice of vaccination, such as duty and power

and risk and faith. Chapter 3 describes the methods used in the research on which the thesis is based and also describes some of the difficulties I encountered in actually carrying out the project. My own personal struggles with being a researcher and the whole process of the research itself from recruiting to analysing the data is explored. The thesis then presents the findings from the interviews in the next three chapters, the analyses chapters. These (chapters 4, 5 and 6) discuss parents' own experiences of the issues surrounding the call to vaccinate. Chapter 4 reveals how they made their decision not to vaccinate, whom or what influenced them and their own views of the science of vaccination. Chapter 5 discusses how not being a vaccinator influenced their personal life; from feelings of anxiety, guilt and isolation to felt harassment from health professionals. The perceived positive effect of not being vaccinated on the health of their children, what is health and what it means to be seen as being different, were all areas brought up by the parents. Chapter 6 considers some of the larger issues which influenced the debate for parents. Such concepts as 'natural immunity' and 'medically acquired immunity', 'herd immunity' and the politics of vaccination and pharmaceuticals are discussed, as accounted by the parents themselves. Finally, chapter 7 draws together the various strands of the study, looks at the implications of the findings and suggests a future research agenda.

The Literature Review Chapter 1 & 2

Chapter 1.

A short history of vaccination and a short history of dissent

Introduction

In studying people's choice not to vaccinate, and their experiences and perceptions of vaccination in the UK, I felt it was necessary to discover how vaccination became a part of accepted medical practice in the first place. In order to accomplish that, there was a need to remind myself of the path medicine has taken particularly over the past 200 years and what led up to the monumental change in emphasis from medicine as a faith-based practice to a practice based on science (Haggard 1929, 1934; Sigerist 1944; Rosen 1958; Ackerknecht 1982; Bollet 1987; Porter 1996; Le Fanue 1999; Winston 1999). To this end, this chapter sets a broad scene providing background context to the detailed investigation of contemporary health beliefs. The historical account presented here is necessarily broad, but identifies key social processes relevant to the thesis as a whole.

In section 1 the emergence of vaccination, Jenner's part in the story and the irrationality of vaccination in a world before microbiology is explored (Haggard 1934). Apart from defining the historical origins of the process of vaccination it also shows how public policy need not necessarily be rational to be implemented and promoted. Section 2 identifies the massive public health improvements that were carried out in the 18th, 19th and 20th centuries and the huge benefits especially to urban populations these changes made, not only to the comfort of the citizens, but also to the health of the entire population. The development and history of the Poor

Law, the Compulsory Vaccination Act set up in 1853 and the development of the Health Service in 1875 are considered. The development of public health as a branch of medicine (or social services) and the relationship of health practice to the law and conventions for the greater good is integral to individual experiences of the health service and vaccinations. Section 3 takes us to the beginnings of bacteriology, Louis Pasteur and the germ theory and Robert Koch who isolated the first microbes from disease sites. This continues with the rapid proliferation of bacteriological discoveries, from antibodies, phagocytes and the discovery of almost all of the known bacterial pathogens and the theoretical foundation underlying the future development of antibiotics and many vaccinations. Bacteriology and microbiology both disciplines founded in the 19th and developed in the 20th century form the rational basis for vaccination as it is practiced today. Section 4, charts vaccination in the twentieth century and the problems encountered with anaphylaxis and the work done in New York to overcome the mass diphtheria epidemic at the end of the 19th century. This is often perceived as the second great positive intervention with vaccines, the first one having been the small pox vaccine. Section 5 looks at the new study of immunology. Immunology quickly gave way to immunochemistry, as chemistry and then biochemistry developed. From the 1950s there are further developments in vaccination and an increasing understanding of how they work and theories about the immune system which underpinned this development. Section 6 charts the development of the vaccination schedules in the UK over the past 30 years primarily to show how quickly the vaccinations are developing and which diseases are targeted in primary care practice in the UK. This is the stage on which the parents interviewed for this research act out their story.

Section 7 takes the chapter into a new direction by focusing on the history of dissent to vaccination. That there was a very strong anti-vaccination lobby from the outset is well documented. Dissenters in the 19th and 20th centuries were on the whole people who had a 'spiritual' outlook on life and preferred a practice of medicine more inline with their philosophical and religious beliefs or they were ardent liberals who did not agree with medicating themselves or their children and viewed vaccination as an infringement of their personal rights. How they demanded freedom from persecution from vaccinators and the compulsory vaccination laws by demonstrating and voting for their rights is examined. This was important in my view, not only as an exploration of the history but, also to be in a position to compare past and present concepts of health, illness and intervention. Lastly the chapter looks to the twentieth century and the world wars. Section 8 takes a short look at the time at the end of the century and the measles, mumps and rubella (MMR) debate which was quite recent and is perhaps still current and brings us up to date. The chapter ends with a summary of the history of both vaccination and opposition to vaccination.

1. Vaccination/Immunisation in the context of the history of medicine.

The history of vaccination/immunisation in western medical practice is just over two hundred years old. Scientifically and socially it has become entangled within other subjects and it is not possible to study it in isolation. It may be better studied and better understood in relation to other areas of science. Areas such as sociology and politics, microbiology, immunology, epidemiology, pharmacology, public health science, the pharmaceutical industry and general medicine, human rights,

philosophy, anthropology, alternative and complementary medicine and medical history; these all impact on the study and understanding of vaccination and vaccination also impacts on these disciplines.

Vaccination as a concept sprang onto the public Western medical stage with the works of Jenner in 1798 with the cowpox inoculation. There are documents that indicate that a similar practice was used in the Middle East in Constantinople (Bazin 2001) and that it was used in many oriental countries before being introduced in Great Britain and in New England, respectively, by Lady Mary Montague and Clergyman Cotton Mather (Bashford *et al.* 2001). Jenner's method prescribed that diseased serum from cows was directly introduced into humans through rubbing a string or a piece of cotton which had been soaked in the cow pox serum into a cut or scratch made on the skin of a person with the belief that it prevented small pox. Subsequently serum from the pustules produced by this method was used to 'inoculate' other people ('variolation') (Jenner 1798)

The practice of vaccination started long before the germ theory was postulated, long before science had agreed concepts of bacteria and viruses, before we knew about what we now call the 'immune system'. It was in fact Jenner, with his (what may now seem to us to be) dangerous and irresponsible methods of infecting people with animal disease matter who started the ball rolling (Jenner 1798, 1799, 1800; Razzell 1977). At the time there was no science of biochemistry associated with the

practice of medicine and it was quite impossible to know what was actually present in the “vaccine” in the way of bacteria, microbes or viruses. The practice of vaccination was thus based entirely on empirical evidence rather than on any theoretical understanding of immunity. While vaccination quickly replaced variolation among medical practitioners, smallpox inoculation continued to be practiced by lay healers, not only because small pox matter was much easier to obtain than vaccine, particularly in times of epidemics, but also because many people preferred to use what they considered “the real thing” (Durbach 2005).

By the early nineteenth century, supporters of vaccination among the medical community had embraced it to such a degree that they believed it was essential that it be encouraged and practiced by medical professionals. As vaccination was a medical process, medical practitioners wanted to control it, not least because it could be a lucrative part of a practice (Durbach 2005).

2. Public Health Improvements

In the 18th, 19th and early 20th centuries, huge strides were made in public health measures all over the world. Serious overcrowding and extreme poverty in the cities of Paris, London and Vienna in the 1700’s was responsible for the breeding of many diseases (Bollet, 1987; Lambert, 1963; Le Fanue, 1999; Foucault, 1974; McKeown, 1965,1966). According to Foucault the first priorities had nothing to do with medication, but solely with rubbish collection, clean water, clean air, new burial grounds, and sewage and quarantine methods. In order to keep the diseases associated with poverty, filth, overcrowding, polluted water and effluent, overused cemeteries,

and bad smells away from the upper classes, physical barriers were set up in the city (Paris and London) to keep the poor out of the wealthier areas. Next the cemeteries were moved out of the centre of the cities to surrounding areas, a rubbish collection service was set up, the water supply was separated from the waste water and effluent was beginning to be channelled into sewers. Foucault describes what he calls “the medicalisation of the city” (Foucault 1974). It was in an attempt to establish the provision of clean air and clean water that chemistry and laboratory science became connected with medicine. Fourcroy and Lavoisier became interested in the problem of organisms in connection with control of the urban air. The first actual public health measures (in modern time) were to do with the environment and started in Paris, not with personal or body health but with environmental measures (Bollet 1987).

By the 1850s, small pox trailed far behind measles, scarlet fever, whooping cough, enteric fever, diarrhoea, dysentery, diphtheria and cholera as a leading cause of death (Lambert 1963). Although little could be done to arrest the spread of cholera, as no one knew how it spread, or what it might be, medical experts and their parliamentary allies believed that compulsory vaccination could be an effective way of attempting to reduce smallpox morbidity (Rosen 1958).

In 1840 a law was passed to outlaw inoculation (which was being performed mostly by non doctor health workers) and to make vaccination, which was carried out by government employed Poor Law medical officers, freely available for the poor. There was little uptake of this service (Anti-Vaccinator 1871) from (Durbach 2005:323).

The Compulsory Vaccination Act, tabled by Lord Lyttleton and supported by the Epidemiological Society, staffed by Seaton and Simon was passed in the spring of

1853, at: “*a late night poorly attended session of Parliament* (Durbach 2005). This act, while introducing mandatory universal infant smallpox vaccination, nevertheless explicitly targeted the poor and working classes (Lambert 1963). The Poor Law made English medicine a social medicine, insofar as this law implied a medical control of the destitute and thereby:

“free the wealthy from the risk of epidemic phenomena issuing from the disadvantaged classes” (Foucault 1974:68).

Diphtheria was rampant in the slums and ghettos of cities both in Europe and America. That the drop in diphtheria morbidity and mortality is not actually due to preventative immunization appears to be indicated by the fact that this decline set in in the nineteenth century before diphtheria antitoxin began to be used generally, and continued progressively even before preventative immunization became wide spread (Rosen 1958). The decline of diphtheria was not an isolated case. Many other important infectious diseases had begun to wane before the full effects of the bacteriological discoveries made themselves felt, from 1870. There was a continuing downward trend in mortality due to a decline in the frequency of certain diseases, chiefly yellow fever, smallpox, typhoid and typhus fevers, malaria and tuberculosis (Rosen 1958; McKeown *et al.* 1966). The initial decline in Typhoid fever coincided with the introduction of proper sewerage systems and even more, of protected water supply (Rosen 1958; Foucault 1974).

In Great Britain, in 1875, John Simon completed the medical legislation for an official service organisation, not treatment but medical control of the population; the Health Service and Health Office(s) were set up. The main purpose of this public health service was very like that of the Poor Law; the control of the health and the bodies of the needy classes; to make them more fit for labour and less dangerous to

the middle classes (Foucault 1975). That people have a 'duty' to remain healthy and not take time off work, nor neglect their 'duties', is still very much part of our culture today (McKeown and Lowe 1966; Foucault 1975; Sontag 1978; Greco 1993; Lupton 1994; Le Fanue 1999; Mason 2001). A kind of morality of conscience entered the public domain which policymaker, public health providers, and health professionals used to promote vaccinations (Foucault 1974; Bollet 1987; Bazin 2001; Colgrove 2006).

3. The Beginnings of Bacteriology

Louis Pasteur first suggested the germ theory in 1857, some seventy five years after Jenner started inoculations. Twenty years later, in 1877, Robert Koch first proved that specific microbes were present at the site of disease in his studies on Anthrax and then Tuberculosis (Brock 1988). This in turn prompted Pasteur to attenuate and introduce microbes to use as vaccines (Pasteur 1881). About this time Eli Metchnikoff, discovered phagocytosis. This discovery introduced the subject of cellular defences against invasion by microbes (Smith 2002). With the discovery of antibodies' activity by Behring and Kitasato, both working in the Koch Institute in Berlin, against diphtheria and tetanus toxins, serotherapy was soon initiated. For years there was a virtual war going on between France for Pasteur with his cellular immunity and Koch in Germany who argued for humoral immunity (Brock 1988; Silverstein 2003). See also the table below.

Table 1. The Discoverers of the Main Bacterial Pathogens Taken from (Brock 1988)

Year	Disease	Organism	Discoverer
1877	Anthrax	Bacillus anthracis	Koch, R.
1878	Suppuration	Staphylococcus	Koch, R.
1879	Gonorrhoea	Neisseria gonorrhoea	Neisser, A.L.S
1880	Typhoid fever	Salmonella typhi	Ebert, C.J.
1881	Suppuration	Streptococcus	Ogston, A.
1882	Tuberculosis	Mycobacterium tuberculosis	Koch, R.
1883	Diphtheria	Corynebacterium diphtheria	Klebs, T.A.E. Loeffler, F.
1884	Tetanus	Clostridium tetani	Nicholaier, A.
1885	Diarrhoea	Escherichia coli	Escherich, T.
1886	Pneumonia	Streptococcus pneumoniae	Fraenkel, A.
1887	Meningitis	Neisseria meningitides	Weischelbaum, A
1888	Food poisoning	Salmonella enteritidis	Gaertner, A.A.H
1892	Gas gangrene	Clostridium perfringens	Welch, W.H.
1894	Plague	Yersinia pestis	Kitisato, S., Yersin, A.J.E (independently)
1896	Botulism	Clostridium botulinum	Van Ermengem, E.M.
1898	Dysentery	Shigella dysenteriae	Shiga, K.
1900	Paratyphoid	Salmonella paratyphi	Schottmüller, H.
1903	Syphilis	Treponema pallidum	Schausinn, F.R. and Hoffman, E.
1906	Whooping cough	Bordetella pertussis	Bordet, J.and Gengou,

Then, in 1897, came Paul Ehrlich's side-chain theory of antibody formation and function, which provided a theoretical foundation for the humoralist cause and the German scientists working at the Koch Institute (Cambrosio *et al.* 1993; Silverstein 2003). Between 1876, when Koch published his first work, and the turn of the century, most of the major bacterial pathogens were isolated and categorised. Most of the discoverers were German or under German influence as is illustrated in Table 1 (Brock 1988)

4. Vaccination in the 20th Century

This takes us to the beginning of the 20th century when it was hoped that not only would it be possible to prevent infection with vaccination, but also to treat them effectively with antibodies (Bosanquet *et al.* 1904).

It wasn't long, 1902, before Charles Richet and Paul Portier hit upon anaphylaxis (Portier 1902). Then "serum sickness", an inflammatory illness caused by the horse serum in which the disease serums, such as diphtheria and scarlet fever were attenuated, was discovered by Arthus in France in 1903, explaining many deaths from vaccinations at the time (Smith 2002).

Accordingly, it was realized that a good deal more knowledge was going to be necessary before the hopes and dreams of physicians and public health bodies of being able to prevent illnesses with vaccines could indeed be realised (Smith 2002).

The first decade of the twentieth century had a solid basis for the control of a number of infectious diseases. For example by 1900, diphtheria could be diagnosed by precise bacteriological methods and sick persons treated with diphtheria antitoxin and well carriers could be tested thus making possible really effective control. From

1885 to 1927 in New York, William Park developed new diphtheria antitoxins and together with his partners Anna Williams and Abraham Zingher set up massive advertising campaigns using flyers, newspaper articles, leaflets public events to alert everyone in the city to the dangers of diphtheria and what they could do to help prevent it (Ramon 1939). These drives were tremendously successful and many other cities followed suit (Silverstein 1989).

5. Immunology

As far as the development of vaccination/immunotherapy was concerned, this stopped almost completely while scientists went about catching up with the science behind disease (Smith 2002). At the beginning of the 20th century immunology was born and for the next 50 years the focus was on learning to understand the physiology of the immune system, and the function and structure of antibodies. Medical immunology quickly gave way to immunochemistry (Silverstein 1989). Antibodies were everything and antibody specific antigens were studied in 1917 by the discoverer of blood groups, Karl Landsteiner (Landsteiner 1962).

By the 1950s most bacteria had been identified, categorized, and characterised. Antibiotics were developed whereby many bacterial diseases could finally be treated effectively. Also antibiotics were instrumental for the discovery and propagation of viruses, necessary for the creation of attenuated live viral vaccines. From the 1950s we once again have new vaccines being developed (but only for viral infections in the mean time) and Pasteur's dream was finally realised (Silverstein 1989). Cellular immunology once again dominated the field, not the cellular immunology of Metchnikoff based on phagocytes, but a cellular immunology based on lymphocytes. T and B cells were defined; the pathogenesis of many

autoimmune diseases and the mechanisms of graft rejection were laid down (Paul 1999).

As laboratory work became ever more sophisticated and the knowledge of the immune system grew, lymphocytes could now (1960) be cultured and it was discovered that they were capable of rapid extensive proliferation in response to mitogens and antigens. Plasma cells by then were known to be the source of antibodies and were found to be derived from lymphocytes. Soon a procedure was developed which showed individual spleen cells as antibody producers (Silverstein 1989). More recent development from the work of Charles Janeway Jr., professor of immunobiology at Yale University, and his colleagues suggest that innate immunity (what is often called 'natural' immunity) is far more important than previously realized. They proposed that the immune system evolved to discriminate self from infectious non-self and that the initial response to infection is initiated by the interaction of pathogen-associated molecular patterns (PAMPs) with pattern recognition receptors (PRRs) on the surface of macrophages and other professional antigen-presenting cells (Janeway 1992). If these theories end up to be confirmed, it would assign to macrophage function a degree of specificity not recognised before (Silverstein 2003). It also suggests the superiority of innate immunity over acquired immunity. Immunology knowledge changes almost daily, making keeping up to date particularly difficult. From one of the definitive immunology text books, which has been updated and reissued seven times in the past 10 years it seems that science now recognises four main sections of the immune system, or four separate types of immune responses. These can be broadly placed in four categories as such:

1. Surface barriers (skin, mucous membranes). The body's first line of defense; the skin and the mucous membranes, along with secretions these membranes produce, are highly effective protectors of immunity.
2. Internal defenses [Phagocytes, fever, nk cells (natural killer cells, innate to the immune system), antimicrobial proteins, inflammation]. The body uses an enormous number of nonspecific cellular and chemical devices to protect itself. The inflammatory response enlists macrophages, mast cells, wbc's (white blood cells or leukocytes), that kill pathogens and help repair tissue.
3. Humoral immunity (B cells)-the first encounter between an immunocompetent but naive lymphocyte and an invading antigen, usually takes place in the spleen or in a lymph node, but it may happen in any lymphoid tissue. If the lymphocyte is a B cell, the challenging antigen provokes the humoral immune response in which antibodies are produced against the challenger.
4. Cellular immunity (T cells or CMIR) - These responses are especially important for destroying intracellular bacteria, eliminating viral infections and destroying tumour cells. When infections or invasions have taken hold within the cells of the body (Gov 2008; Murphy 2008).

This is only the tip of the iceberg; the literature on immunology is vast and very much in the realm of microbiology and outside of the scope of this thesis. It is clear from my reading, which only skimmed the surface of this huge field, that the development of immunsations/vaccinations has added a great deal to the confidence of physicians and the public health world to be able to support and treat patients when infectious diseases threaten. It has also become clear that there is a very long way to go in terms of knowledge, theory development and research, to be confident about what is actually changed in the body and in society with the introduction of vaccinations/immunisations and what, if any, the long term and hidden affects might be (Stone 1986; Schreibner 1993; Pellegrino 1998; Le Fanue 1999; Freeman *et al.* 2002; Smith 2002; Jackson 2003; Hardon *et al.* 2005; Murphy 2008).

6. Vaccination today and the pharmaceutical industry

The vaccination industry is huge and is no longer only part of medicine, but has become part of economics, part of the business world (Blume *et al.* 2000). With its strong links to the medical establishment and public health services the vaccination industry has managed to gain a unique position in the market place. It does not have to pay its frontline salesmen (GPs) nor fund its own retail outlets (GP surgeries), this is all paid for (in the UK) by the tax payer. This puts them in a unique position in our capitalist society; a business which is partly funded and supported by the state. The following extract indicates the size of the market the pharmaceutical industry enjoys:

“GlaxoSmithKline and Aventis Pasteur, who both claim a 24-percent share of the \$6.5 billion-a-year global vaccine market, said demand was being driven by new products, including combination jabs and new adult treatments. The infant sector currently accounts for two-thirds of vaccine sales but market dynamics are changing, helped by growing demand for flu shots among the elderly and increased use of vaccines by tourists visiting tropical countries.....global vaccine sales would rise by more than a fifth to about \$8 billion by 2005, underlying a long-term trend which has seen a tenfold increase in sales since 1980, while drug sales have risen only five times. ..Both GSK and Howd, biotechnology analyst at ABN AMRO, said vaccines were now one of the fastest-growing areas of healthcare, with demand for new products outweighing supply, and the total market set to top \$10 billion by 2010”-- (Hirschler 2002).

Pharmaceutical companies who now create vaccines are by and large big companies with a combined annual turnover of US\$ 680 Billion (ttmc. 2008). They are listed on the stock exchange with huge marketing budgets and strategies that involve governments and their health departments, universities, the World Health Organisation (WHO), UNICEF (United Nations Children’s Fund) and countless other for profit and charitable organisations right down to individual doctors and patients.

The most transparent method of showing the progression and development of routine childhood vaccination practice in Britain is to actually include the schedules for GP practices. (see Appendix 1).

As can be seen from the data in Appendix 1, the number of recommended vaccines for a child in the UK in 1988 was 17; this has more than doubled to 38 in 2008. Not only is there an increase in the number of vaccinations for children, but the whole protocol has shifted. Vaccines are now repeated more and more frequently as the science of immunology has discovered that memory cells are deleted and new ones generated which need reminding of the antigens they are meant to be responsive to (Gray 2002).

One could perhaps say that a new science of vaccination, sometimes called Vaccinology, is gaining mastery of the practice of vaccination. But, as suggested by Plotkin, vaccinology lacks context:

“I don’t see easily how anyone could master all the aspects that go into vaccinology. People who practice vaccinology may be epidemiologists who have no deep insights into immunology; they may be field workers who know how to get vaccines into people but who have no concept of vaccine development whatsoever” (Plotkin 1998:15).

He suggests that those people who now make and sell the vaccinations to the government health departments, are not, as was previously the case (when the inventors were the owners of the vaccines) the people who know enough about them to see the whole picture, who understand the vaccines and their effects from all aspects. The people (usually teams of laboratory scientists and biochemists) who now create the vaccines are creating a product for a market. It is up to public health scientists, the government and perhaps sociologists and anthropologists to ensure this relationship is not misused.

Professor Stuart Blume from Amsterdam University has written extensively on vaccinations, both from a scientific, historical and sociological point of view, he said the following on vaccinology:

“The current use of the term vaccinology has to be understood in terms of the two transformations which vaccines research and development has undergone in the past 15± 20 years. The first is the introduction of new techniques for making vaccines, deploying modern biotechnology, genetics and immunology. The second is the increasingly important and now dominant role which private industry has come to play” (Blume and Geesink 2000:120).

Prior to the 1980's, institutional relationships were rooted in a common commitment to public health (Cohon 1998). Since vaccination research and development are no longer under the exclusive control of universities or scientific institutions and have become part of the commercial pharmaceutical companies, the knowledge generated in the new vaccinological networks is no longer freely available. By becoming part of the commercial world, vaccines have increasingly become protected by patents and intellectual property rights.

“To access research and development technology, national producers have to enter into agreements with commercial producers which seriously affects their intellectual freedom” (Freeman and Robbins 2002:83).

Suggesting rather less than open and ethically safe practices. The position of vaccine development in 2008 in a society where innovation depends on investment is not all that secure. Vaccine manufacturers can make much more money on drugs for diseases than they can on vaccines and some companies have ceased making them altogether (Freeman and Robbins 2002; Hardon and Blume 2005). There are differences of opinion that vary from those that state that ‘vaccinations are a big earners’, to the opposite stance of ‘vaccinations are not viable’. Sociologically there are also dilemmas. Colgrove in his book about the state of vaccination in the US:

“The history of vaccination cannot be viewed as a teleological narrative in which scientific advances produced a steady stream of increasingly sophisticated vaccines, leading to ever-greater levels of infectious disease control” (Colgrove 2006 : 286).

It isn't straight forward, health and illness are in constant flux, and diseases come and go, despite everyone's best efforts to control them.

Apart from the standard vaccines promoted for all children, there are many others readily available (see Appendix 1a). (This is included here to give an idea of the types of diseases targeted by vaccines in the UK)

7. Short History of Dissent

From the very beginning there have been scientists, philosophers, health workers and members of the public, for whom the practice of vaccination was problematic; who didn't believe it was the right thing to do. They had, and still have, a different approach, a different understanding, a different way of looking at life than the rationalistic viewpoint generally promoted as acceptable in the area of scientific knowledge and medicinal practice. When science took over the ownership, management and development of medicine the rationalists turned their back on Hippocratic medicine.

Hippocratic medicine, as initially formulated by Hippocrates in ancient Greece 400BC, has some very different points of view as very briefly pointed out in the following quote:

“It was the treatment of an individual not a disease, and the treatment of a whole body, not of any part of it. The treatment was based on the fundamental assumption that nature, physis, had a strong healing force and tendency of its own, and that the main role of the physician was to assist nature in this healing process, rather than to direct it arbitrarily. Health was a state of harmonic mixture of the humors (eucrasia), and disease was a state of faulty mixture (dyscrasia)” (Ackerknecht 1982:18).

The medicine of Hippocrates and later the Aristotelian inspired medicine of Galen in the second century AD and Paracelsus in the sixteenth century placed the concept of vitality and the interconnectedness of the world of nature, the cosmos and mankind centrally in medical practice and thinking (Greene 2004). The seventeenth century French philosopher and mathematician, René Descartes and Thomas Hobbes in England were responsible for expressing the changes in perception within society; from seeing nature, and the human body,

.... *“as part of a ‘purposeful’ vital world to that of a machine subject only to the immutable, universal laws measurable and fixed”* (Porter 1996:68).

When vaccinations were first proposed as common practice in 1840’s and made mandatory in 1853, there was enormous opposition to the new philosophy and practice, particularly in Great Britain (Durbach 2005). One of the better known and vociferous sceptics was the eminent scientist and colleague of Charles Darwin, Alfred Russell Wallace (Fichman, 2007; Lancet 1888, 1897, 1898, 1934). There were many such objectors from all walks of life. Many were Quakers or Swedenborgians, Theosophists or Spiritualists who often objected on moral, religious and ethical grounds. Alternative medical practitioners; homeopaths, herbalists, mesmerists, hydro therapists, all busy practitioners in mid nineteenth century Britain, all opposed vaccination (Durbach 2005). Durbach noted that:

“A belief in vaccination is at variance with the theories of all the ‘pathies’ and ‘isms’” (Durbach 2005:33).

The ACVL (anti compulsory vaccination league) was formed in 1866 by the vegetarian and food reformer Richard Gibbs. This organisation had over 103 branches by 1871. By this time the labour movement also opposed vaccination and the anti-vaccination movement operated as a type of medical reformation movement.

The new feminist movement or women's suffrage movement as it was at the time, opposed vaccination. To quote Mary Hume-Rothery (a suffragette leader at the time) writing in a bulletin against the practice of compulsory vaccination:

"Freeborn English-women can no longer call their bodies or their babies their own" (Hume-Rothery 1871:3).

According to Hume-Rothery feminists at the time felt their very bodies invaded and their rights as protector and carer of their own babies taken away from them by the vaccinators and the government by making vaccinations mandatory (Durbach 2005). Making vaccination a civil rights issue.

The ACVL grew and grew. People were still fined for not vaccinating, and sent to prison for not paying their fines, but all this was grist to the mill of anti-vaccinators as they made public spectacles and parties out of their protests. Events with sometimes 80-100 thousand participants marching through cities and gathering on village greens to protest and air their grievances was not unusual (Durbach 2005). In the 1906 parliamentary election 174 MPS (all Liberals and all voted into office on the anti-vaccination platform) signed a petition demanding the entire repeal of the vaccination acts (Lancet 1897, 1907; Durbach 2005). By 1907 one could obtain a certificate claiming conscientious objector status to avoid prosecution for not vaccinating. By 1910 the anti-vaccination movement along with its prominent leaders had more or less ended as there was no more need of it (Colgrove 2006). The medical profession was gaining power in Britain, despite public oppositions to their philosophies and practices.

One story in the history of the anti vaccination history, particularly relevant for Edinburgh University and for vaccination perception and CAM therapies, is the story of Thomas Richard Allinson (1858-1918) a graduate of the Royal College of

Physicians of Edinburgh in 1879, who became a naturopath, favoured “natural healing” and was strongly anti vaccinationist as were most of his naturopathically inclined medically trained colleagues. He became very popular, had a column in The Weekly Times and Echo, promoted vegetarianism, debunked medications and doctors and wrote a pamphlet entitled; “How to Avoid Vaccination”. He was struck off the medical register for advertising. He was so popular and successful that he was able to purchase a flour mill and bakery and Allinson’s bread was born (still on the market to this day, as is the flour) (Brown 1991).

As noted earlier, there were no new vaccine developments in the first half of the twentieth century; perhaps because of the enormous transformations caused by WW1, the Spanish flu epidemic which raged through Europe and America in 1918-20, the great depression in the thirties and WW2 (Porter 1996). The UK government repealed vaccination requirements altogether in 1946 because nearly half of parents in many areas were claiming conscientious exemptions (Salmon *et al.* 2006). New drugs had been invented, most likely to deal with infections and diseases of the war wounded. Sulphonamides and Antibiotics were the new hope, the “cure-alls”, in the middle of the twentieth century (Cooter 2003). When Salk and Sabin developed, with much trial and error and changes of direction, the new vaccine for the devastating polio outbreak of the 1940s and 50s (Heller 2008) it was the first large scale vaccination development since the diphtheria triumph and the turn around for the reputation and popularity of vaccination.

a. Opposition to Vaccinations in the 21st Century

Opposition to vaccination is international. One only has to go to the web to find references to non-vaccination from all corners of the globe. In many ways objectors may be seen as followers on, as the inheritors of the AVL ideology, the suffragette movement and the reform movement. Members of such groups as Amnesty International, Green Peace, the Vegetarian Society, anti-vivisectionists, animal rights groups, peace and civil liberty groups, organic gardeners, naturopaths, chiropractors and homeopaths and their patients and some religious movements and churches may all potentially be non vaccinators because of their belief systems (Jamison 2001). Vaccination objection is frequently clandestine and hidden from scrutiny by health professionals and from other people generally (Colgrove 2006).

That that triad of medical authority; medicine, government, public health, wield great power is indicated by the absence of a law regarding compulsory vaccination in the UK (apart from in the military where it is still compulsory and within some professions). Vaccination by law is a big issue in France and in the USA, and for travellers to some countries. Even though it isn't legally compulsory in the UK, one could argue that legal compulsion has been replaced by a moral duty imposed by a medical discourse that overwhelmingly promotes vaccination and tends to castigate refusers as either ignorant of the benefits or irresponsible in terms of their own children's health and of the health of the population in general (Rogers *et al.* 1995; Leach *et al.* 2007). In 2004, the British Medical Association revisited the issue of compulsory vaccination, partly because of decreases in vaccine coverage for measles, mumps, and rubella (MMR) that resulted from the widespread concern about associations between MMR and autism (Folb 2004). The British Medical

Association concluded that compulsory vaccination was not appropriate for the UK and supported a 2002 Scottish Executive Report, which concluded that,

“Such a policy is not consistent with key elements of the frameworks or principles for immunisation policy. On a practical level, it is not self evident that it would lead to higher levels of immunisation. More substantively, it runs counter to the core principle that vaccines should be administered on a voluntary basis” (Scottish Executive, 2002/2005).

Perhaps the British people, due to many factors too complex to go into here, respond better to moral and ethical compulsion rather than legal measure which caused such rebellion in the past.

In a research project undertaken with GPs in Ireland, researching their relationships with non-vaccinating patients it wasn't the science that was seen as an issue for the GPs, but the moral and ethical issues around having to persuade parents who had misgivings that was found to be problematic (Alderson *et al.* 1997).

8. The MMR debate

Within the past 15 years, the UK had a series of unique events in the public health world, these were; the vCJD outbreak in 1990s, attributed to butcher's practices and animal husbandry (NCJDSU) 2008), the Bristol experience, where heavily promoted research debunked the very popular complementary cancer care support therapies, in Bristol in the 1990s, as making no real difference to outcome, and the whole-cell pertussis vaccination scare (permanent brain damaged from pertussis vaccine. When the vaccine was linked to cot deaths in the early 1980s it became a public “scandal” and the vaccine was subsequently altered) (Geier and Geier 2002). These events may have eroded public confidence in the medical profession and their recommendations (Folb 2004). The most likely single event to have influenced the

recent resurgence of open public opposition to vaccination was Andrew Wakefield's research published in the Lancet in February 1998 (Wakefield *et al.*, 1998). He had been commissioned to undertake this research by parents of children with learning difficulties, who had difficulties with communication, social problems and health issues. Children with the type of symptoms concerned are more and more frequently diagnosed with autism, or autistic spectrum disorder. The research was based on parents linking the onset of behavioural symptoms with the MMR the measles, mumps, and rubella vaccination. In the concluding paragraphs the researchers said:

"We have identified a chronic enterocolitis in children that may be related to neuropsychiatric dysfunction. In most cases, onset of symptoms was after measles, mumps, and rubella immunisation. Further investigations are needed to examine this" (Wakefield *et al.* 1998)

This single article became a major bone of contention for the medical profession causing colossal upheavals within the scientific community and generating public concern about immunisation and their possible adverse effects. It also led to questions the extent of the benefits of MMR. Many articles have been written as a consequence of Wakefield's research being published, disagreeing with his findings (Taylor *et al.* 1999; Fombonne *et al.* 2001; Halsey *et al.* 2001; Madsen 2002). A kind of academic panic set in, in an attempt to disprove Dr. Wakefield's findings; this spilled over into the press, the radio and television for a number of years. Often an 'expert' would be denigrating the Wakefield research and reassuring the public that vaccines were safe (Bower 1998; Kmietowicz 2001; Bedford *et al.* 2003; Dobson 2003; Jackson 2003). Andrew Wakefield then tried to persuade the NHS to provide single vaccines, as it was thought that this might have been less harmful, but there wasn't a budget available to provide these on a large scale (Burgess *et al.* 2006).

Parents did manage to acquire these for their children privately however (Skea *et al.* 2008).

A number of research projects have been carried out looking at how parent make decisions about vaccination for their children (Evans 2001), how decision-making has changed (Burgess 1994; Telford *et al.* 2003; Salmon *et al.* 2006; Samad *et al.* 2006; Racine *et al.* 2007) and to evaluate the effect of all the controversy on the public opinion and awareness (Andrews 2006; Casiday 2006; Chen 1999; Evans *et al.* 2001; Hilton *et al.* 2007; Hobson-West 2007; Jackson 2003; Kmietowicz 2007; Poltorak, 2007) One example published in the BMJ, which on the whole did not support Dr Wakefield's research, did find that the controversy has affected parents of autistic children:

"Of the 38 parents, 28 thought that the MMR vaccine may have contributed to their child's autism" from BMJ News pages (Kmietowicz 2007).

However, the drop in MMR uptake (Miller 2002) was very small when taken over the whole country. The fear talked about, that people would stop taking the vaccinations because of the autism scare, hasn't happened on a large scale. Although TV campaigns such as those that warned the public of new measles outbreaks just around the corner would make one think otherwise. The organisations and unorganised groups of people who openly either question the practice of routine, or who actively recommend either more research or single, vaccinations (of MMR for example), are many. Some such as JABS, Informed Parent, National Vaccine Information Centre, NVIC in the USA the Australian AVN have an active membership and online presence (Wolfe *et al.* 2002:431) and from my own investigations I have found that natural childbirth groups and homeopathic and

herbal patient groups, vegetarians, Christian scientists, some; Muslim, Hindu, Buddhist and Jewish groups, have a multiplicity of attitudes to the conventional practice of mass childhood vaccination, not infrequently to abstain from participating.

To sum up this section; while the MMR controversy has had significant impact on vaccination awareness in the UK it has not significantly altered uptake in the long term. One of the main significant contributing factors to vaccination awareness and vaccination program participation/rejection is the obvious one of target demographics, generally children are only targeted directly after birth and while in an active relationship with the NHS. It may be that as they grow up, and remain well, this relationship weakens and vaccination awareness fades.

Summary and conclusion

In this chapter I have attempted to trace how the widespread immunisation programmes in the UK and elsewhere can only be understood in light of the complex interplay between history, faith, science, sociology, and politics and with economic factors at work. I have also tried to trace the footprints of the anti vaccination “movement” which briefly flourished in the 19th century and to find out if and how it is still with us today.

From Hippocrates to laboratory medicine, from doctors as healers, as promoters of healing to doctors as scientists, as managers of the workings within the human body, the past 2000 years has seen tremendous changes in the practice of medicine (Lambert 1963; Foucault 1974; Bollet 1987; Freeman 1992; Le Fanue 1999; Colgrove 2006; Fichman 2007). Laboratory sciences have given us amazing insights into the workings of the body. By far the most effective measures for the promotion

of health for large numbers of people have been the public health and hygiene measures and the abolition of poverty (Lambert 1963; Foucault 1974; Bollet 1987; Le Fanue 1999; Colgrove 2006; Fichman 2007). Decent housing, clean water and adequate food have saved the majority of the population from disease, suffering and early death (Rosen 1958). Those who still needed medical treatment after they had all three of the above may not have been made any “healthier” with vaccinations, possible by surgery, or an antibiotic, or a herbal or homeopathic remedy, or some other supportive and health promoting method (Douglas 1992). The science of vaccination in the beginning of the 21st century has become so difficult and so specialised a subject that the government health promoting bodies, the family GP or practice nurse, those at the forefront of vaccine promotion, have been obliged to create metaphors to sell this service to the public (Henderson, R *et al.* 2004).

Before going on to discuss the aims and methodology of this study in detail later in chapter 3, the next chapter, chapter 2 will review the sociological contribution to understanding vaccination and in particular public knowledge.

Chapter 2. The Sociology of Vaccination.

Introduction

In the process of researching people's perceptions on vaccination, particularly of those parents who made a conscious decision not to vaccinate their children, the work of medical sociologists and the anthropology of health and illness became the first and then the central underlying field of study for this project. In the previous chapter I focussed on the history of vaccination and the history of non compliance in an attempt to set the stage on which the story of the present day situation vis a vis vaccination can be comprehended. It is the purpose of this chapter to explore the literature surrounding non professional perceptions of what vaccinations are and how they fit into the concepts of health and illness held by various groups in modern Western society. The sheer breadth and depth of work done by sociologists on the subject of health and illness, was for me rather daunting initially as there was so much and there were so many different voices. When I was able to get a little bit of a handle on the progressive element of the subject, the progress of changes over time, and learned more about the different schools and areas of study, things became much more comprehensible, interesting and engaging. Initially, coming to the subject of medical sociology and anthropology from a non or newly academic perspective, having been a parent and occasional patient for many years, a consumer, and a professional health practitioner also, to realise that there were so many different sociologists who study our behaviour was at first quite a novel revelation. It was Lupton's book on the Medicine as Culture which really opened up the world of the

sociology of health and illness in a way that made me feel able to engage with the subject. Much of the literature within sociology seemed to me to be analytical or descriptive, often without a moral purpose, or if there was a purpose it was often a negative purpose, or a struggle for power. I couldn't see how that kind of sociology would create a quantum leap in improving the health of the people; it would only replace one set of rules with another set of rules. When what I thought what was really needed to actually create health and healthier people, is a change of consciousness or a paradigm shift. This speaks perhaps of bigger issues, about the purpose of sociology and medical sociology in particular and about the distinction between the sociology 'in' medicine and 'of' medicine (Strauss and Corbin 1990).

In an attempt to address the type of questions and issues that came up during my interactions with the respondents and my own reactions to the process, quite a broad area of sociology was made use of. This chapter covers some quite diverse subjects. In Section 1, the short comings of a bio medical model of health and illness are discussed from a sociological point of view and also the emergence of vaccination as a product of this model. The development of patient power and the doctor-patient relationship is touched upon. The lack of spirituality within the health practitioner/patient relationship was noted and a brief look at the hospice movement as a place where the medical model used by bio-medicine attempts to include concepts of spirituality and personalisation was next explored (Saunders 1981; Vivat 2006). This then leads to a brief discussion on the need for a philosophy of medicine and indeed a need for a definition of what medicine, or the practice or profession of medicine, actually is.

In Section 2, duty, power and preventative medicine are discussed in the following areas: vaccination inhabits the area of *preventive* medicine, within our society we now have a *duty* to stay healthy (Greco 1993) and the state exercises its *power* persuade us to be healthy (Zola 1972; Illich 1976, 1977; Martin 1994; Gabe 1995; Nettleton 1995; Lupton 1999; Nettleton 2006).

Section 3 explores risk, faith and informed consent. Parent's who question the vaccination program do so for many reasons. Sometimes they have lost faith in bio medicine and/or in the ability of their GP to give them the right advice. This prompted me look at the concept of faith more generally and the connection between faith, religion and making choices in health care intervention. I found that these intertwining areas of social being are particularly lucidly described in Rayna Rapp's writings (Rapp 1998, 2000). The subject "risk" as a sociological area of study is next to be explored and has been heavily researched and well documented (Douglas 1992; Scott 1992; Gabe 1995; Lupton 1999). There are many journals dedicated to risk research, such as "Health, risk and society", "The Journal of Risk Research", "Journal of Risk and Reliability", "Risk", "Risk Analysis" to name but a few. Having read a number of books and articles on the subject, I might have written more, but the vaccination debate, in terms of 'risk' in the literature in medical sociology isn't very comprehensive.

Section 4 explores and considers some of the research carried out by others on the subject of vaccination within sociology and public health.

Section 5 addresses the complex issue of informed consent as it relates particularly to parents and vaccinations. Before proceeding with a medical

intervention, the law requires there to have been a negotiation between the patient and the health professional to establish informed consent (DHS 2008).

In the last section of this chapter, section 6, the role of women and especially mothers as health carers within families is discussed. Some of the feminist aspects from the sociological literature are looked at and the role of women in decision making when it comes to vaccinating their children is explored. The chapter ends with a short summary.

1. The biomedical model and dualism

The biomedical model of medicine with which we work in our day to day healthcare is experienced by many people as somewhat impersonal or inhuman in its approach to disease and suffering. In an attempt to subjugate healing to a scientific method medicine has had so some extend to base the practice of medicine on:

“a Cartesian division of man into a soulless mortal machine capable of mechanistic explanation and manipulation, and a bodiless soul, immortal, immaterial, and properly subject to religious authority, but largely unnecessary to account for physical disease and healing” (Osherson et al. 1981)

It seems that we are guilty of somehow having split mankind in two; body and soul, separate and not integrated. Biomedicine is frequently accused of focusing almost exclusively on the body;

“It often treats the person in that body as of no consequence whatsoever. The body is deemed to be the patient, because it has the ‘disease’” (Turner 1984:84).

Patients can find this extremely frustrating, because the doctor is looking for a disease, where most patients want relief from their illness.

“...patients suffer ‘illnesses’; physicians diagnose and treat ‘disease’...illnesses are experiences of disvalued changes in states of being and social function: diseases are abnormalities in the structure and function of body organ systems” (Eisenberg 1977).

There seems to be little room for concepts of soul, or spirit, mind or individuality within bio-medicine. Many medical professionals will also struggle with this question in their daily practice, as they are human issues affecting us all. As expressed by Turner...

“Medical theory offers a subtly articulated expression of the person’s alienation from the body in Western society, but this alienation is found, as well, in every sphere of economic and political life” (Turner 1984:24).

How to transcend the mind-body dualism is and has been a dilemma for mankind for a long time in all areas of human endeavour. Cecil Helman writes about an alternative to mind/body dualism as shown in the study of the categories through which physical and psychological states are cognitised, labelled, ordered and acted upon.

“In this view, “mind,” “emotions”, personality”, “body”, and “organs” are all cultural categories, which are socially derived” (Helman 1988).

As an Anthropologist Helman sees perhaps more than dualism, he sees the human being in medicine as consisting of many separate parts that all have their separate realities.

According to Cassell, the only way of transcending this dualism in health care at this point in time is to shift from a *“preoccupation with causes to an emphasis on care”* (Cassell 1982:16). Which sounds to me like a practical way of getting started in solving some of these dilemmas.

The emphasis on care is nowhere more noticeable than in the hospice movement. Here have been attempts to include spirituality in healthcare with the care for terminally ill patients, with not a great deal of success according to one research project undertaken in Scotland recently (Vivat 2006). Guidelines from the Scottish Executive on hospice care expressly mention spirituality and spiritual care as an

important and valid aspect of clients need (Government 2009). Cicely Saunders and others established the St. Christopher's Hospice in South London in the early sixties. The aim was to create a new kind of hospice with a completely different approach to the care of the dying to that in allopathic medicine (Saunders 1981). For Saunders and other pioneers of the hospice movement, something was missing from the allopathic medical concept of health, illness and disease, particularly in relation to the needs of dying people.

Perhaps it is not necessarily spirituality that is the missing ingredient, perhaps it is more a respect and support for other people's different views of life, there are after all plenty of people who complain about their doctor, or the health service, who do not express themselves using the word 'spirituality' or 'religion' at all.

Generally, still, in the UK, bio-medicine is a rational medicine. And, *"Rationality has come to stand for the mental pole in the dualistic opposition of mind and body"* (Kirkmayer 1988).

If this is true, and mind has replaced spirit in a secular world then doctors have replaced priests as the carriers of wisdom and knowledge (Zola 1972; Illich 1976).

'The doctor knows best', is an oft assumed assumption. Dualism is perhaps an experience of the present state of being, as it comes up everywhere.

"The real dualism", according to Sullivan, *"is not between two substances (mind and body) but between the physician as active knower and the patient as active known"* (Sullivan 1986).

This certainly goes a long way to shedding light on the problems some of the respondents in my research brought up when discussing their interactions with health professionals, vis-à-vis not believing in vaccination.

The relationship between the patient and their doctor has changed enormously, especially within the past 20 years noted by many including Bakx:

“The nature of professional –lay interactions are changing and there is a marked decline in faith in bio-medicine” (Bakx 1991).

With the arrival of the internet, increased access to further education and the enormous general interest in everything ‘health’, people have access to information hitherto not possible (Shaw *et al.* 2004). This may be partially responsible for some people’s unhappiness with the status quo. Other issues such as that medicine fails to account for the social inequalities in health by focussing solely on the biological changes within the body is another area focussed on by sociologists (Engel 1981). Throughout the history of bio medicine there has been strong opposition to its exclusiveness and many attempts at extending the practice of medicine to include a more spiritual bio-psycho-social element has been tried and largely thwarted (Armstrong 2002; Douglas 1992; Kuhn 1962; Ogden 2002).

Bio medicine does come under much criticism from medical sociologist and anthropologists. Illich for example argues that biomedicine does more harm than good. Rather than curing and healing, he says, medicine actually contributes to illness through the iatrogenic effects of its interventions, such as side effects of drugs and the sometimes negative clinical consequences of surgery (Illich 1976). He also draws attention to the fact that people have lost confidence in their capacities to take care of themselves and their families, and that the professions allied to medicine have disempowered people so they can no longer take responsibility for themselves.

To conclude, bio-medicine seems to be an incomplete model of healthcare. To be able to answer the complex and manifold needs of patients, or consumers, it needs a whole other side that can address the emotional, spiritual and social aspects of human kind, and not just the biological, chemical and structural aspects of the

body or its diseases. The person in the body wants to be addressed within context of his or her own culture.

2. Duty, Power and Prevention

The practice of vaccination inhabits the arena of interventionist medicine as a subsection of bio medicine. When a child is presented for immunisation it is usually not ill, if it is ill it will generally not be vaccinated. Therefore a vaccination is not a treatment per se; it is seen as a preventative measure. It is generally assumed that people do not want to be ill. That people have a duty to be and stay well is a much documented idea mentioned in a whole cornucopia of sociological and anthropological literature (Foucault 1975, 1980; Sontag 1978; Nettleton 1995; Herzlich 1987; Martin 1994) to mention but a few. When a parent is promised freedom from illnesses for their child by the simple method of a little prick in the arm at no financial cost to themselves, they will invariably feel duty bound to comply. Morally and practically they feel there is no choice; when those who are supposed to know the answers, the professionals, say it is the best thing to do, even when, within their own being, it feels wrong (Rogers and Pilgrim 1995). The felt pressure from the health visitor and practice nurse persuades them to do 'what is best'. This persuasive power is internally derived:

"Western medicine claims that it is based on objective science, which in turn involves empirical observation and induction. Medicine thus claims to offer the only valid response to the understanding of disease and illness" (Nettleton 1995; 2006:37).

Richard Freeman heralds a "*new politics of prevention*" (Freeman 1992).

"We prevent what is 'bad' in order to promote what is 'good'" (Freeman 1992:35).

Preventative medicine, thought to have been such a good idea by the DHSS in 1977 is proving a difficult policy to put into practice (Henry *et al.* 1987). It requires that people conform and behave in ways they might not necessarily agree with.

Preventative medicine therefore can become an act of government.

“Preventative policy reflects two dominant concerns on the part of the state: these relate, perhaps self evidently, to the security of its subjects, but they also include the security of security, that is of the prevailing social and political order and of the place of government and the state within it” (Freeman 1992:86).

He also quotes Stone,

“The new political line-up often has labour, women’s groups, parent groups, advocates for women and children, and a new breed of ethics watchers pitted against medical researchers, public health advocates and industry” (Stone 1986:686).

These groups may be seen as revolutionaries against the system by some, but they often have righteous heart felt anger, disappointment and dismay about the system and want to change it.

There is a substantial body of work, perhaps initially championed by feminist sociologists and anthropologists in particular, that emphasise the paternalism of preventative measures, and of course the protection of individual rights. In looking at how vaccinations are viewed by some of the representatives of the type of social groups that Stone above may have had in mind, the picture becomes very muddled by anger, condemnation and accusation. For example Schreibner, who has acted as an expert witness in several court cases for vaccine damage cases in the US, accuses society, particularly medical practitioners of being guilty and that by embracing vaccination as a medical intervention, society has legitimised the *“ritual abuse of babies”* (Schreibner 1993). Or to put it more mildly; or anthropologically perhaps;

“The ritual of vaccination has become a rite of passage, it has replaced baptism, the religious protection afforded by the church”, or circumcision, “with the secular protection of vaccination” (Moscovitz 1988:2).

Vaccinations are not mandatory in the UK. The majority of the population may not be actively aware that they need to make a decision on whether to go ahead and have the vaccinations for themselves and their children or not. The way it is presented to them, by a card in the post alerting them to their child’s appointment for vaccination from their local GP, does not ask them if they would like the vaccinations, it just gives them an appointment to attend a clinic (NHS 2008). It assumes that they will comply. It does not ask them to make a choice; the choice is made for them. For those people who do have an opinion on the subject, or who have studied and decided not to have the vaccinations, this attitude may be seen as being arrogant on the part of the NHS (Bloor 1990). For those who do question the programme or who find this attitude patronising, this method may provoke their anger, as it questions both their integrity and their intelligence (Poltorak *et al.* 2007). Perhaps,

“The technocracy that plans, organises and delivers vaccinations has its roots in an earlier ethic of public health, and in more assertive social planning” (Leach and Fairhead 2007).

That:

“Power provokes resistance” (Bloor 1990:210)

where he is talking about Foucault’s work on analysing power in prisons, can happen in the medical setting also. Resisters to routine childhood vaccination are increasing in number (Leach 2007). This may be due to a growing development in alternative views on health, it may also be due to the social pressure people feel they are subjected to and object to (Leask *et al.* 2003). When people do discover that they

have a choice and they have had sufficient time to study the options and do the reading necessary to be fully informed, they may decide to postpone the vaccinations (Poltorak 2007). Once they are out of the loop of the early years' vaccination programme, and they believe that they have seen that there are benefits to not being vaccinated for their children, they may even abandon any thoughts of vaccinations altogether (Leach, 2007).

3. Risk and Faith, Change and Anxiety

The subject of 'risk' has been much talked about and researched in sociology, as in other areas of human economic, social, medical and intellectual endeavours. From superstition to insurance, risk seems to have been a part of our daily experience for at least a thousand years if not longer (Lupton 1999; Jaeger 2001). The sociology of risk has become a major area of study in sociology. The story of risk perception and the application of cultural theory to issues of risk indicate a paradigm shift in emerging theories (Jaeger 2001). Even the meaning of the word 'risk' has undergone many changes (Lupton 1999).

"People have very different understandings and opinion about risk" (Jaeger 2001).

When non-vaccinating parents discuss the pros and cons of vaccination with a health professional, the subject of risk often comes up. Health professionals assure parents that the risks of the possible damage of the disease outweigh the risks of the vaccination (Leach 2007). Nurses and public health professionals have been sensitised to the public health concepts of risk, parents often haven't. What a professional health worker sees as risk seems to be different to what a parent thinks when he/she hears the word 'risk'. The professional may be concerned with statistics

of public health science and the possible rise in communicable diseases within society, where the parent is concerned with the quality of life and the health of their own individual child and their responsibility as a parent (Streefland 2001).

“...whereas experts define risk in a narrow, technical way, the public has a richer, more complex view that incorporates value-laden considerations such as equity, catastrophic potential, and controllability” (Slovic 1992).

There are many ways to define risk, and risk assessment is usually done either in a positivist or in a constructivist manner (Lupton 1999).

“The most widely used definition of risk, a convention, is derived from positivism; risk is the probability of an adverse event (e.g. injury, disease, death) times the consequences of that event (e.g. number of injuries or deaths, types and severity of diseases)” (Wilson et al. 1987).

Cultural theory sees risk, for example, as a representation of collective belief systems. Within cultural theory the concept of risk is seen to be culturally embedded, and socially constructed and agreed.

“A key shift required by the perspective described here is that definitions of risk, and knowledge, and responses to information and uncertainty are based ultimately on the attempted maintenance of familiar social identities . . . Physical risks thus have to be recognized as embedded within and shaped by social relations and the continual negotiation of our social identities” (Wynne 1992:178).

There is a real reluctance by constructivists to define risk which stems from an,

“Aristotelian, anti-essentialist disposition that is unaccepting of definitional ‘essences’” (Rosa 1998).

A logical continuation of this ‘anti-essentialist’ position is to say that since risk does not exist, it exists only in the collective mind of people; that is, through a shared understanding that we call culture. Risk, then, is nothing more than what different groups of people think it is. This brings in a new definition of risk as Reconstructed Realism (RR):

“Risk is a situation or event where something of human value (including humans themselves) has been put at stake and where the outcome is uncertain” (Rosa 1998).

This definition fulfils our present task. It expresses ontology (a theory of being).

RR or reconstructed realism itself stems from social behaviourist George Herbert Mead’s philosophical works, specifically his ‘Scientific Method and the Individual Thinker’ (Mead 1964). There is a definite connection between risk and uncertainty.

In many ways, the concept of risk explains that there is an uncertainty present.

Science as we use it today in common practice has no place for uncertainty, it only deals in certainties. The concepts of risk and uncertainty also challenges science, explained by Rosa thus:

“... the modern world has generated a set of problems demanding scientific understanding, but which are too complex or too ambiguous (indeed, often laden with ‘in eradicable uncertainties’) to yield to science alone” (Rosa 1998:23).

Funtowics and Rafetz acknowledge that understanding and decision making must take place in a value-laden context. The ordinary practice of science is unprepared for uncertainty and values. As a consequence, science is an essential but incomplete knowledge system for many of the environmental and other risk problems facing the world (Rosa 1998). This core idea that science cannot adequately address issues of risk as been explored by a number of thinkers for a number of years, example:

“the new problems facing our industrial civilization, although requiring scientific inputs for their resolution, involve a problem-solving activity that is different in character from the kind that we have previously taken for granted” (Funtowicz et al. 1992:965).

This relates to my research in that some non-vaccinators may feel that they do not need a risk assessment from the NHS to make their decision, they may not even trust the NHS, they have a healthy child and do not want to risk damaging it with a chemical intervention (Leach, 2007).

“ Lay people have become sceptical about science, because they are aware that science has produced many of the risks about which they are concerned and that scientific knowledge about risk is incomplete and often contradictory, failing to solve the problems it has created” (Lupton 1999:38).

Most likely, much larger paradigm shifts within society are involved in this change in trust, risk and faith in the medical establishment and government policy. Our world is changing constantly and:

“Whether one uses the term high modernity, post-modernity or risk society, we live in a new type of social order, where systems of expertise and science have lost their monopoly on truth” (Beck 1992).

Though outwardly life in the western world has become exponentially a ‘safer’ place; no world wars, no plague, plenty food and clean water, no highway robbery etc., peoples’ perception, people’s stories say otherwise. We are obsessed with risk. From removing all the germs on your cutting board in the kitchen, as adverts on the television claim will keep your baby healthy, to endless insurance policies for everything from accidents on school outings, to vaccinations for 12 year old girls to prevent cervical cancer. Why are we all so fearful now? That society has changed and is changing ever more rapidly may be the principle cause for the increased anxiety and increased perceptions of risk noted by not only sociologists, but everyone who reflects on society.

“All these changes are associated with a sense of uncertainty, complexity, ambivalence and disaster, a growing distrust of social institutions and traditional authorities and an increasing awareness of threats inherent in everyday life” (Luhman 1993:43).

From my reading I discovered the many ways sociology addresses the emerging risk paradigm and how the concepts of risk have infiltrated almost every area of human endeavour. Both Anthony Giddens and Ulrich Beck have developed

theoretical frames that place risk at the core of the world transition (Giddens 1991; Beck 1992). The dangers of technology and the very science we rely on to help us be safe, have become a risk factor to cope with.

“We inhabit a culture highly sensitive to risk and as Armstrong (1991) has pointed out, the threats come from everywhere –from the air that we breathe, the rays of the sun, the multi-national petrochemical companies, the ‘man’ in the street, from our families, our sexual partners....even the cell of our bodies may turn against us” (Scott 1992:3).

Risk analyses then is something we all do continuously throughout the day as part of everything we do, every choice we make, every step we take. On a bigger scale risk analyses is very much part of the world of economics and has become a potent tool especially in the hands of the pharmaceutical industry and for politicians.

The positivistic scientific approach to risk analyses makes making sense of the non-vaccinators’ view on ‘risk’ well nigh impossible. This problem is very well described by Emily Martin:

“The length of time it took me to make this stuff stand as vivid testimony to how solidly entrenched our own cultural presuppositions are and how difficult it is to dig them up for inspection. The one I stumbled over was my acceptance of scientific, medical statements as truth, despite many warnings I had made to myself and heard from others about precisely this kind of danger when one tries to do fieldwork in one’s own society. Berger and Luckmann have expressed this problem as ‘trying to push a bus in which you are riding’” (Martin 1987:2).

Within the world of risk, we have acceptable and unacceptable risks. As expressed well by Jaeger:

“Acceptable risks are those that do not pose a cultural threat. In such cases, a comparison of costs and benefits for individual actors is still an option for guiding individual decisions. Unacceptable risks, in contrast, threaten the culture by undermining vital cultural presuppositions – unacceptable for the socio-cultural fabric as a whole. Their assessment does not allow individual actors to advance arguments based on assessments of costs and benefits, because they undermine the sense of ontological security provided by community culture ” (Jaeger 2001:259).

What is acceptable risk for one person, or indeed not considered to be a risk at all, may not be a safe or even a viable risk to another. This brings us to ‘risk anxiety’. Recent social theory has conceptualised risk anxiety as a social state engendered by an increasing lack of trust in both the project of modernity and expert knowledges (Beck 1992; Giddens 1990, 1991; Scott, 1992). The fusion of risk anxiety with protectiveness engenders a preoccupation with prevention (Freeman 1992). This is the landscape of the vaccination mindset, the coming together of risk anxiety and the preoccupation with prevention. Life for parents has suddenly become even more difficult because now;

“Parents are not only responsible for caring for their children they are also held responsible for their children’s well-being” (Andrews 2006).

Risk consciousness and the changes in risk awareness are likely to be behind the development and exponential proliferation of vaccinations and all other pharmaceuticals, but at the same time they are also responsible for the opposite, for the non vaccination and anti-pharma stance.

4. Vaccination research

Vaccinations have changed, maybe forever, the way we experience and expect to experience the world. They straddle a range of scientific, academic, political, economic and social disciplines, making no one group their exclusive guardian and making charting their course or steering their development very complex.

In searching for the sociology and anthropology of vaccinations, I have come across only a handful of studies that frame the subject in a post-modern constructivist

and reflexive way. There are many studies on vaccinations but they are by and large informed by public health and are not objective, they are biased toward the increase and proliferation of social control with vaccination. The following research papers are perhaps somewhat different than others in that they make an attempt to understand how parent think and make decisions and do not necessarily come from the ‘need to control’ point of view.

To begin with I will start with a short discussion on a paper published in 1991 by Suzanne New from the University of Lancaster and Martin Senior from University of Salford called “I don’t believe in needles”(New *et al.* 1991). The paper represents the qualitative data that emerged from a largely quantitative case-controlled study on the uptake of infant immunisation in two district health authorities in the North West of England. The reason I go so far back in time to include this study here is mainly to highlight how two particular aspects of the sociology of vaccination have had an important role to play in the development of this field of knowledge. These are:

1. The effect of vaccination failure/damage and the influence of the press on vaccination uptake, and,
2. The importance of carrying out qualitative research for ascertaining more accurate knowledge about the reasons people don’t vaccinate.

The paper starts by placing the vaccination debate in the present (relative to when it was undertaken) through its more recent historical framing. The ‘pertussis scandal’ of 1974-1986, (when a significant number of children were allegedly brain damaged by certain pertussis vaccines) may have caused great harm to the vaccination programmes both in the UK and the USA, with uptake falling as low a

9% in some areas (Baker 2003). The newspapers at the time were full of articles about parents and their terrible ordeals from damage to their children's health caused by the vaccine. That health professionals, in the UK particularly, were also often "against" vaccination, or colluded with parents to avoid the pertussis vaccine was quite unique, this didn't occur or wasn't recorded in the USA or other European countries (Baker 2003).

Initially it was believed that parents didn't bring their children into the clinic for vaccinations because of transport and time-space constraints. By developing the research to include at least some qualitative aspects, the basis for a more comprehensive and perhaps more realistic outcome was engendered.

The research consisted of a structured questionnaire, targeting 634 mothers. Contacts were taken from the DHS Child Health System data for those who had been immunised and from the routinely generated list for health visitors of:

"defaulters without a reason given for two appointments in succession" (New *et al.* 1991:511).

Interviews with 234 women were in the end achieved; these appear to have been questionnaire based with space for open ended and parental knowledge and attitude questions near the end. Thereby generating some qualitative data for the research.

Perhaps it is noteworthy that there were only two categories for vaccination status in this study; they were termed either; "Complete Immunisers", or "Incomplete Immunisers". Which meant that non-immunisers, a category perhaps overlooked at the beginning, were not adequately represented in the research? This oversight or shortcoming was also acknowledged by the authors as:

“...a group which was therefore at best unrepresented within the sample (New et al. 1991: 511).”

One of the principle outcomes of the research was that it was not always the practical issues such as transport, or the illness of the child in question or the lack of time of busy mothers that prevented them from getting the vaccinations for their children. The rigour of this project brought out hidden reasons, reasons more difficult to articulate than just the practical issues such as lack of transport, illness, or inability to attend with small children in tow which were often used as easy excuses for not attending for vaccination appointments. Reasoning of a more personal nature and most likely more influential on their decision making, such as:

“This woman was one of at least eight women who felt that if their child caught whooping cough, even though they were aware in many cases of its potential severity, it was something out of their control and ultimately survivable, whereas if their child was left brain damaged as a result of vaccine damage, it would be entirely their fault” (New et al. 1991:513).

They also discovered that that their two categories may have been too restrictive, as they found four women amongst their group of 71 incomplete immunisers who were completely set against immunisation of any kind. They discovered by using qualitative interviewing methods with these women that they had done a lot of research and found their own evidence to support their views. One of these mothers had changed from being a vaccinator to becoming a non vaccinator because she believed that her eldest son had developed an allergy in reaction to his first injection. Since she had previously been told that he would not suffer any side effects, she was understandably now suspicious of the advice offered by health professionals.

The researchers included many ideas and opinions previously brought up by other similarly intentioned research but they took their research a step further by adding another dimension to their methods which consequently informed the outcome. This is perhaps best illustrated by this quote from the paper:

“It should never be assumed therefore that it is a decision which is easily or unthinkingly made, for although the decision of parents may sometimes be at variance with the expectations of professionals, the overwhelming majority of parents are only seeking to do what they think is in the best interest of their child” (New et al. 1991:516).

This very complex and rich sociological and geographical research paper ends with the words of one of the respondents:

“I think it’s a personal decision...Parents should have the final word and that’s that, the end of the subject” (New et al. 1991:518)

Next I want to discuss another research report which is very recent and from the US. I put this here first of all to highlight the changes in the development of the subject but also because the researchers approached the subject from a very different premise. Sometimes it seems that we get more new knowledge about a subject by studying its absence than forever going over again and again what we already know. This is what Gullion, Gullion and Henry did in Texas as described in an article entitled “Deciding to Opt out of Childhood Vaccination Mandates” (Gullion 2008) Quite recently published in Public Health Nursing, (based in Massachusetts USA), this article describes a research project undertaken by a county health department chief epidemiologist in Texas, and two assistant professors of sociology, one from the University of North Texas and from the other from Texas Wesleyan University. Their research questions were:

1. *“What is the decision process by which parents conclude to forgo vaccinations for their children?”*
2. *“How do parents process information on the pros and cons of vaccinating their children?”* (Gullion, 2008:401)

They interviewed 25 people, who lived in Northern Texas, which is mostly rural, selected using snowball and targeted sampling:

“Both techniques have been shown to be useful in gaining access to otherwise hidden groups and as a means for soliciting data on stigmatised behaviour” (Gullion, 2008: 404).

(It was also my finding, that non vaccinators could be stigmatised and made to feel bad about their choice). The respondents all had above average education (as did my respondents). Another simile was the following:

“Most (88%) mentioned aspects of their life that could be categorised as “alternative living”, such as vegan/vegetarianism; organic gardening; using of natural healing remedies, including herbals and homeopathics; and chiropractic for primary health care. Mention of use of midwives and natural childbirth and breastfeeding were also frequent” (Gullion, 2008:405).

I found the similarities to the research I had done interesting as it showed that the thoughts, feelings and experiences that lay behind non-vaccination may be global, or at least not constricted to the UK. However, some of their conclusions were different from mine. For example, the researchers mention that their non vaccinators or “vaccination refusers” as they sometimes named them here, belong to an actual “movement”. There is no mention that the people they interviewed felt themselves to be part of a movement. But the words: “the ant vaccination movement”, is used in the article when referring to those people who object to vaccinations for their children. Personally I do not see it as a “movement”, mainly because the people involved are not organised and they are not usually politically motivated and they did

not talk about wanting to influence others. Although there were some exceptions. The report mentions how some of the respondents argued that their civil rights, including the right to determine the liberty of their children, are being violated, and that the government (which included public health workers in their eyes) is misleading the public about the safety of vaccines and is influenced by highly profitable pharmaceutical companies.

Philosophical exemption is now an acceptable criteria used by parents to avoid compulsory vaccination for their children in the USA. Introduced in 1999 it is now accepted in 19 US States (Gullion 2008: 402).

According to Gullion and her colleagues:

“There has been a recent increase in individuals who refer to themselves as “conscientious objectors” to vaccines or who are “philosophically opposed” to vaccines” (Gullion 2008: 401).

This is a change in policy in the USA, as previously only the religious objection was accepted as a reason for not having a child vaccinated before attending school.

One rather unique aspects of this research is expressed on the first line of the conclusion where the researchers say:

“It is easy to slip into a discourse of “right” and “wrong” when exploring vaccination use and exemptions” (Gullion 2008:407).

The danger of slipping into the “right” and “wrong” of it, of whether it is better to believe in vaccination or not to believe in it, has coloured almost all the research undertaken by others and is of course irrelevant when undertaking a project to ascertain peoples opinions and choice in healthcare intervention. That one phrase about “right” and “wrong” makes this research project unique in my opinion, and

incredibly valuable. It creates new possibilities for dialogue as stated by the authors themselves in their concluding paragraph:

“With this project we hope to open the door to further study of this group and to open avenues for dialog between public health practitioners and parents who opt out of childhood vaccination” (Gullion 2008:407).

The article focussed on next describes a research project carried out in 2003. I have included it here because it deals with an aspect that I have been very interested in myself, but haven't yet been able to pursue. It also suggests that there may be large groups of people living within this country, part of our society, who are totally overlooked and not either accepted or supported by the NHS because of a different outlook on health and on life, a non biomedical outlook perhaps.

This study, undertaken in 2003 by Henderson, Millett and Thorogood, investigated the reasons for the low uptake (43%) of childhood immunisations in the orthodox Jewish community in London (estimated 20,000 members) (Henderson *et al.* 2008). Twenty-five Jewish orthodox mothers were interviewed and recorded and the narratives were transcribed and analysed. Several salient factors were uncovered which pertain to the perceptions intrinsic to relatively closed communities. Such as, that they felt safe from outside infections because they don't mix much with the outside world, that they are healthy, they spend more money and effort keeping healthy than non community members as this is a 'religious' requirement (I would add that it may be cultural as well as religious), and that they had an intrinsic and informal social network where they discussed their health needs. The weaknesses of this study, clearly mentioned in the report itself, were that since the research was carried out under the auspices of the NHS and with the support of local GP practices, those families targeted may well have been unusual as they were more open to

‘outsiders’, which may be associated with a greater willingness to immunize. And for similar reasons, those members of this community who may not use Western medicine at all, were not recruited. This may have given a one sided view of things.

For me the one disappointing aspect of the project was that it didn’t enter into the underlying belief system or reasoning of the orthodox Jewish community’s attempts at avoiding vaccinations, in any meaningful way. Perhaps because it was funded by the local primary care trust which may have initiated the research project with the intention of increasing vaccination uptake in this community. So I’m not sure if it contributes to the sociology of vaccination very directly; indirectly it highlight that this community of over 20,000 people in North London, tend to be suspicious of vaccinations. The researchers have highlighted some very important ethical points about interviewing people from religious and ethnic minorities, about ‘gatekeepers’ and gaining access to communities and about what it is possible to achieve within this kind of public health framework. Perhaps the success of the research is not in the outcomes for the NHS, but in exposing the health service as being unable to get close to these people and be of service to them because of the different belief systems. ‘Twenty thousand people in London are not supported by the NHS because they don’t believe in vaccinations’, this may be an exaggeration, as many of them did have some vaccinations, but it demonstrates how divisive and limiting having one form of healthcare in a country as diverse as the UK is.

Perhaps another project with this community, carried out from within the community itself, or in collaboration with the community, with the purpose of learning from them and listening to them. If researchers could hear what the researched believe, think and feel, and record how they deal with health issues, it

might inform us how to develop our health service to be more inclusive and more diverse. To create a dialogue with a large ethnic minority could help create more diversity and harmony, socially and politically and inform the health service on how best to be of service to this and potentially many other groups of people.

The next project I will describe was carried out in Scotland in 2003 as a PhD with the MRC unit at Glasgow University. The article here quoted wasn't published till 2007 (although four others were published previously). As previously mentioned, the MMR debate spawned a plethora of papers and dominated the media for a number of years. Almost all the papers published about the MMR debate have been bio-medical in orientation and defensive in character. This one by Hilton, Pettigrew and Hunt is no different in that respect (Hilton et al. 2006). They undertook this research via a series of 18 qualitative focus groups across central Scotland in 2002-2003. Using purposive sampling to ensure maximum variation among parents (64 mothers and 8 fathers) with small (3-5 people in each) focus groups. The main focus of the study was to ascertain people's perceptions of the dangers of MMR vaccine.

"The purpose of the analyses was to examine parent's views and the role the media, politicians and health professionals have played in providing credible evidence about MMR safety" (Hilton et al 2007: 1471).

From my initial reading of the research set out in this article, her results seem not unlike like mine in many aspects, except that only four of her respondents' children were completely unvaccinated and they were all from one family. Other than that, the questions the respondents asked and the conclusions the researcher came up with, such as: that there is not enough research available for parents to make an informed choice, that many parents thought that doctors and scientists are not to be trusted, that it is hard to know who to go to for impartial advice, that some parents had been

ostracised for not having the recommended vaccines, that doctors are not impartial and that the truth is suppressed and that Dr Wakefield is a “whistleblower” who is on the side of parents, also came up similarly in my research as questions/conclusions that respondents had. Which in turn suggests to me that many of the questions parents have about vaccinations are much more common than perhaps realised? The main focus of this article, intended for public health, was the issue of trust and credibility and the media and learning lessons on how to prevent a decline in public confidence from a health scare such as the ‘MMR and autism’ vaccine scare in the future. The PhD on which this article is based does go into parents’ understanding of vaccinations in more depth. An element of how parents discuss the difficult and highly charged subjects and how they negotiate what they won’t say in public is also brought to fore. The section on her interviews and the analyses with the parents of autistic children is particularly memorable and moving.

The contribution this project has been able to make to focus group research methods and pitfalls, is perhaps even greater than the contribution to the sociology of vaccination itself.

The following research is of a completely different nature and I have included it here, not because it is in any way a sociological research project, but just to show how internet research with this subject has been done. Undertaken by an internet entrepreneur called Heininger and called “An internet-based survey on parental attitudes towards immunization” and published in the *Journal Vaccine* (Heininger 2006).

The research is quantitative and is based on German parents and their vaccination attitudes and knowledge. This research was undertaken entirely on the

internet, as a voluntary user experience survey on a help and support website for new parents to find out more about why people might refuse vaccines, in order to inform vaccine uptake criteria.

A self administered questionnaire was placed on the website in May 2004. It comprised of 13 questions with multiple-choice answers. The time to complete the survey was estimated at from 10-15 minutes. The survey was advertised to 62,000 families in a newsletter. The survey was conducted over a 6 day period and 6025 questionnaires were filled in and returned online. The results are interesting even though it is a rather short cut way of ascertaining people's views on the subject. One important difference between how such a survey might conclude in the UK from this one held in Germany, is that in this survey parents put their paediatrician at the top of their list of who they would trust for vaccination advice. People in the UK, who generally do not have 'a paediatrician', might not trust their GP in quite the same way. That the website and the researcher received funding from Sarnoff Pasteur MSD is regrettable and makes it in my view and most likely to other sociologists and parents also, unreliable and not trustworthy.

Once I knew who had paid for the research I went back to the research questions to look at them through the eyes of a vaccine manufacturer/supplier. Suddenly, all the questions looked rather different; the questions are framed to gather information for marketing and implementation strategies. For example the question: How tolerable are combination vaccines compared to single immunizations? The answers are to be chosen from; "Better", "The same", "Less" or "I don't know". This would provide some information on how people view this issue from a public

health and sociological perspective, but it provides much more for the provider of the vaccines on how best to market their product.

A number of research projects have been undertaken and papers have been published about “non compliance” to the vaccination policy, some of them are named in the attached bibliography; see: Chen, 1999; Leask, 2003; Marshall, 2001; Peltola, 2000; Salmon, 2006; Samad, 2006; Smailbegovic, 2003; Streefland, 1999; Tandon, 1996; The Lancet , 2007; Tickner, 2007; Verweij, 2004. Some acknowledge the existence of intentional non-vaccinators, as opposed to non-vaccinators by default, but most tend to see non-vaccinators as “non-compliers” and are therefore perhaps already biased against them.

In my own research I felt strongly that I also wanted to:

“empower respondents to encourage them to find and speak in their own ‘voices’” (Mishler 1986).

I hope I have been able to do that and thereby get some deeper insight into why they chose not to vaccinate and find out more about their health beliefs.

5. Informed Consent

Any medical intervention poses a risk, or even multiple risks. These can be physical, psychological or social risks. Vaccinations are no exceptions and are subject to the need for a risk assessment. Parents, if they feel their responsibility for their children’s health duly, will attempt to assess the risks. That they have done so, and do accept the risks as far as they may be understood or indeed known would be demonstrated by the signing of, or agreeing to, an informed consent document. This is an area where medical sociology, ethics, philosophy and the law interact. That this

will be a very difficult goal to achieve has been recognised and perhaps is the reason why it is taking so long to achieve. For many reasons, one being;

“The vast literature on informed consent, found in journals and books of medicine, law, bioethics, philosophy and public policy, has been stimulated by the need to create a workable doctrine that can accommodate values that to many observers are in an irremediable state of conflict” (Berg 2002:3).

The medical profession hasn't yet caught up with accepting that there is a need for genuine informed consent. According to Doyle, much more work needs to be done if we are to come to some kind of overarching agreement between the people affected, professionals and policymakers to make it a workable process that satisfies the needs it is meant to address (Doyal 2001). Informed consent as a concept began to be used after the Nuremburg trials as a consequence of the outcry against the atrocities inflicted on the prisoners of war and those people thought to be undesirables by the Nazi regime (Faden 1986).

“Informed consent has emerged as an issue both of great importance and substantial uncertainty and confusion” (Gray 1978).

The purposes of informed consent can be confusing. It can be used to protect the recipient of the consent from litigation for instance. This brings up the ethical versus legal functions of informed consent. There can be a distinction between informed consent and consent forms. There is even a suggestion that informed consent is an ideal that can never be achieved. Gray argues that:

“Informed consent is presently not a reliable method of protecting subjects and patients from harm because of limited commitment of professionals to the concept of informed consent, the tendency for procedures to be substituted for substance, the dependence of the quality of consent on many factors, including the characteristics of the subjects or patients, and the tendency of human subjects review committees to confine their attention to consent forms rather than to the process by which consent is sought” (Gray 1978:46).

In the context of vaccinations, informed consent may be too difficult a subject to get true informed consent for at this point in time. GPs themselves haven't the time to explain all the pros and cons for all the vaccinations dispensed under their supervision, nor are they specifically trained in vaccinology, biochemistry, epidemiology or the alternatives. They are not impartial themselves as there is a payment scheme in operation in the UK for the carrying out of vaccinating patients (BMA 2008). This makes the giving of impartial information and therefore secure 'informed consent' ethically quite difficult (if not impossible).

Since WWII, and the Nuremburg trials, ethical and morally responsible medicine has become an important part of the way we want medicine to be practiced and research to be carried out, laid down and agreed in the Helsinki Declaration in 1964 (WMA 1964). In the UK, informed consent is a legal obligation in relation to vaccination, enshrined in the 1998 Human Rights act.

"It is the health care professional's responsibility to make sure the patient knows the basic information, understands why it is important to know the options open, and is given the opportunity to change their mind at any time" (BBC 2000:web; Executive 2008).

If we are to follow such thinking, informed consent will not be a possible option when it comes to vaccinations as no options, and no alternatives are offered by the health service apart from choosing not to have them.

6. Women as Health Promoters, the role of the mother

Primary health care is the term conventionally used for the first port of call when there is a health problem. In reality, everyone knows that the 'real' primary health care does not happen at the GP clinic, it happens in the home. The first port of

call for a child or other adult, who is feeling unwell, is the mother, the parent, the woman. The knowledge that women are the main health carers in society is well established and accepted (Oakley 1974, 1981; Graham, Hilary 1984; Cunningham-Burley *et al.* 1990). Not only do women monitor and maintain the biological wellbeing within the family, but many other aspects of the community life such as the social, the economic, the practical, clothing, housing, food, rest, culture, care of the elderly; these aspects are all controlled by and large by the women in the community (Doyle 1995; Morris 2005). All these aspects are vital to the health of the members of the community and/or family. Over the past 30 years women's groups, self help groups and women's health collectives have sprung up and declined again (Collective 1993). But all the while women have been bringing up their children, making myriads of daily decisions about the healthcare of their children and family members (Cunningham-Burley 1990). Making such choices as whether to take them to a doctor or not, to consult an alternative practitioner or to use a well known family remedy for an ailment or complaint has made the woman in the family the first port of call, the initial decision maker in family healthcare, the primary carer (Lupton 1999). That all this health work, worry and responsibility goes unremunerated as part of their 'natural' role (Stacey 1988), is usually the case and is deplored by feminists. That women have had to sacrifice their identity and much of their power to 'motherhood' is also remarked upon (Oakley 1993) as a feminist issue.

I have not found any exclusively feminist writings specifically related to the subject of vaccination. In the wider context of childcare and mothering a great deal of work has been done by feminist sociologists, particular when it comes to

childbirth and women's right to choose. Many of the same arguments and thought processes that underpinned the debates on 'natural' childbirth could just as well be about non-vaccination (Edwards 2005; Kitinger 2007). The arguments for more autonomy, more self regulations, for independence in childbirth, for less intervention for a "natural child-birth" are very similar to the arguments used by non-vaccinators. Their overarching themes are empowerment and self determination and freedom from pollution and intervention.

Summary

The main focus of this chapter has been to place the objections and oppositions to the routine practice of vaccination into a current sociological/anthropological framework.

The rationalistic world informing the bio medical model of medicine does not relate to 'health' particularly easily, the idea "health" is perhaps not a rational concept. The focus in bio medicine is on pathology. A human body, body- part, or cell is deemed healthy in bio medicine by the virtue of the absence of disease. Bacteria, viruses, growths, abnormalities, breaks, damage, these are the type of words used for describing 'disease' when in a more holistic approach these are seen as the result of illnesses, not the illnesses themselves. That 'disease' is the main focus of bio-medicine may be one of the fundamental obstacles to better communication between health professionals (vaccinators in this case) and non-vaccinators. This may mean that unless bio medicine becomes more inclusive and widens its remit the two may never be able to agree.

Parents who don't vaccinate may become radicalised, they may become dissenters of bio-medicine altogether in their attempt to protect their children from

what they understand to be an assault on their child's immune system with vaccinations. The misuse of power within the doctor-patient relationship also has a role to play in alienating patients; a well researched theme in medical sociology, which is expanded upon later in this dissertation in chapter 5.

Within society, people assume a responsibility to be healthy, to keep their children healthy and this usually means not being ill, not having a disease. People most likely participate in the vaccination protocol because they are promised freedom from disease by complying. However, when health professional promoting the practice use emotional coercion rather than rational facts to persuade them to comply parents sense that there is something wrong with the vaccination policy and it puts them off, it makes them suspicious of the vaccinator's motives.

The idea that risk, explored in medical sociology in some depth, has two different faces, one for public health and one for individual situations and that these two are not compatible was also looked at in the literature and is an important factor in the vaccination debate.

The research carried out with parents shows that they are becoming increasingly more concerned, anxious and distrustful of the premise that vaccinating their children is always a good thing. There seem to be pockets of people within society and groups of like minded people who do not believe that vaccinations are either necessary or desirable.

It is not yet possible to fully implement the practice of "informed consent", for various reasons, but particularly because of the complicated and specialist knowledge required, by health professionals, to explain how vaccinations work, and by parents to be conversant in the scientific language needed to rationalise

vaccinations. The faith needed between practitioner and patient, to trust the practitioner enough to vaccinate, in the absence of scientific rigour, can be absent (Freeman and Robbins 2002) and should, in a rationalistic environment, not be necessary.

With an occasional exception, it is the women in families and in society who carry the role of primary carer, health promoter and decision maker when it comes to; the home, education, nutrition, clothing, hygiene, behaviour, religion and health interventions including vaccinations

Chapter 3 Research Method

Introduction.

Chapter three focuses on the methods used in the project, how the project was achieved, the difficulties that had to be overcome and the steps that needed to be taken to do the interviews and to analyse the data and write it all up.

The sections in the chapter are by and large chronologically arranged, from preliminary work done before I started the MPhil, a short section on ethics which was an important theme for me throughout the project and then the changing of my orientation from practitioner to researcher and finding a new approach and new voice. The chapter then continues with the practicalities of recruiting the respondents, doing the interviews and other associated fieldwork. Next a short section about the respondents and interviews themselves. A section on the methods used for analysing the data follows. The chapter ends with an exploration of the strengths and limitations of the methods used for the research and the implications these have for the findings and conclusions and finally a short summary of the chapter.

1. Preliminary Work

In my homeopathic practice I have frequently seen patients who had grave concerns about vaccinating their children. They felt unsupported by mainstream medicine in their beliefs and life style choices. They sought both the support of other like-minded parents and health professionals with more holistic perspectives with whom they could feel more comfortable. To support these people I set up and facilitated focus/discussion groups. These group discussions took place from 1997-

2001 on average bi-monthly, both in Edinburgh and Glasgow. This work was set up as a service for self-referred clients who were concerned about vaccinations and felt the need to discuss the subject in a non-threatening supportive environment. These were group discussions held in alternative and complementary health centre meeting rooms, in church halls, and within a school. They were advertised locally within nurseries, schools and libraries and in health related commercial outlets. As well as field notes and observation notes, some quantitative data was generated mostly for business and accounting purposes and to gain an understanding of the participants and their needs (appendix 2 shows a sample the data). The work was not seen as research at the time, but as a service.

As a direct result of hearing all their stories, I gained more insights into how people think about this issue and the kind of questions they have and how they cope with the consequences of their decisions. As a consequence of this work I became ever more interested in how people make choices in health care and wanted to research this further. Had I known more about qualitative research at the time and had I had more resources, I might have used these opportunities to do a study similar to Jenny Kitzinger's AIDS Media Research Project (1994). She, like me, was not only interested in,

“What people thought but in how they thought and why they thought as they did. Such research objectives necessitated the use of in-depth work; we opted for group work because of our interest in the social context of public understandings”
(Kitzinger 1994:173).

I then found a way to do this research within the University. However, without funding and with very little support, focus group research was not an option

for me; additionally, as noted below, I wanted to explore people's own accounts in some depth.

2. From Practitioner to Researcher

The actual methods used in the MPhil study developed over time and changed according to my learning and experience. I began with reading and reviewing the sociological literature around the subject (see previous chapters). I did not realise at the time, the amount of work and time commitment needed; first to become acquainted with the literature, but especially to adjust my frame of mind to academic enquiry. To change from being a homeopath - someone who listens to patients in a certain way with the intention of helping them with a specific problem - to someone who listens to a person with the intention of hearing how they think and make decisions, required much self observation, time to process and much reading to discover ways of articulating the changing paradigms. As time went on I intentionally saw fewer patients and expanded the amount of reading I was doing, which helped enormously and subsequently sociology and anthropology became increasingly more interesting, understandable and worthwhile in helping me frame and formulate thoughts and ideas around the subject of researching people's health beliefs.

3. Pilot study

When the time came to do interviews for the initial pilot study of the MPhil, I chose the respondents from people I had met in my work as a homeopath and from some of the people who had been at the vaccination workshops and my own immediate community. I used a topic guide, and open ended questions. The topic guide was informed by various sources: by the questions from participants as they

were voiced in the preliminary workshops, from the questions put to me by individual patients in consultations and from reading the literature surrounding vaccination issues. Even though the questions were mostly open ended I began to notice that the questions themselves already included many of the presumptions I held myself, either from the group discussions I had been involved with or from my own personal questions/dilemmas around the subject. I also noticed that the order of asking questions affects the line of thinking of participants, driving them in specific directions. I felt I was influencing the outcome of the interview far too much by steering the conversation into preordained directions. I kept hearing phrases and points of view that sounded very much like my own words or ones I'd read in books. I was also aware that the people who had been my patients before, and people who knew who I was, were possibly not saying their own words but were somehow trying to please me, saying what they thought I wanted to hear. This felt unsafe to me in my capacity as a medical sociology/ anthropology researcher as it was not objective or sufficiently detached. I was imposing my view of reality and asking the respondent to fit in with my choice of questions, which was not what I wanted to do. Sometimes I felt that it was me who was being researched to see how much I had influenced the respondents. This period of reflection on my own role was very important and helped me to become a reflexive researcher. I have not included these interviews in this study although they have influenced my progress and thinking a great deal, as has the previous work with focus/discussion groups. What I now wanted to accomplish with my research was to get to their reality. To do that, I would need to find out what their questions were. What I was looking for with my

research was not the “what” but the “why” and “how” of people’s decision making which needs interpretist thinking and construction (Creswell *et al.* 2007).

4. Ethics

During this time I became increasingly concerned about the ethics surrounding the subject and the potential misuse of my research outcomes. Like many of the respondents, I had developed scepticism of the ethics and morality of the pharmaceutical industry and big business. I was worried my work might be hijacked by the pro-vaccinators: by informing them how non-vaccinators think and make decisions and where they get their information from, it might therefore inadvertently be playing into their hands. I know it sounds absurd in this context. There were times, though, over the past 30 years that the media portrayed some worrying stories about abuse against non-vaccinators. One respondent told me about a court case in Ireland where a child was taken away from its mother by social services because she was seen as an unfit mother due to her stance on vaccination. This is it here:

“In May 1995, armed police and social workers arrived at a house where a baby girl had just been born to take her away to be immunized against hepatitis B. Her parents were happy for her to have immunoglobulin, but had once expressed serious doubts about vaccination because it caused a severe skin rash in her elder brother. No further effort was made to discuss the problem with them. Instead, within hours of her birth, a public health doctor arranged for a High Court judge to make her a ward of court and to order her immunization without the parents having any chance to be heard. Nine months later, the High Court still has not heard them or their medical experts, yet the wardship continues in case the child needs an unprecedented fourth injection” (Nicholson 1996:4).

As unbelievable as it sounds, and of course we don’t know the background, this happened in the UK and is just one example. One respondent in particular was very worried about this aspect of my project, about what my interview with her might provide in the way of evidence to a court. All I could say to her was that I

understood her anxiety and that I would be very careful to keep everything anonymous, which I have done. Several people mentioned their anxiety about compulsory vaccination becoming law in this country, as it is in some others and what this would mean for them as non-vaccinators. Would they have to leave the country, or go into hiding? These kinds of questions alerted me to the great variation in how people feel about their responsibility as parents and about power and potential abuse of power by those that provide social and primary health care. It also made me aware of the similarities and differences between my own sense of responsibility as a parent and the experience of my respondents when it comes to health care for their families. This may be because I grew up in two different cultures myself, the Netherlands and the USA, in cultures where the population is perhaps more individualistic and somewhat freer from government health policy control and more personally and philosophically led when it comes to making health care decisions than is the case in the UK. It might also have nothing to do with that at all. The USA has some mandatory vaccination policies, but they are quite easily avoided by those who don't believe in them. My own family were pioneers to some extent and immigrants, who had to think for themselves and provide their own healthcare. The respondents in my research live in a society where healthcare is provided by the state and where vaccinations are free at the point of delivery. This is a very different scenario which engenders different responsibilities, preconceptions and outcomes. To my mind some of the non-vaccinators I worked with felt themselves to be vulnerable outsiders who had to hide their beliefs from their immediate community for fear of being ostracised (Mitchell 1993).

Through my previous work with patients and years of listening to people and being interested in people, I have become aware that the interview itself can have quite powerful effects on the people involved. Even though I was not acting as a health care practitioner in this context as researcher, and therefore not directly subject to my professional Code of Ethics, I was nevertheless very aware at all times of the need to adhere to the principle of 'Do No Harm'. It even became an issue for me that I felt a responsibility to support the respondents and turn the experience of being interviewed into a therapeutic, or at least not a 'damaging', experience. This in itself shows perhaps that there was still an element of the health practitioner in me and the thin line that exists between establishing rapport and being empathetic, and being therapeutic. Because I did not elicit any respondents from government run or NHS organisations, getting official medical ethics approval was not an issue for me. This made me all the more conscious of being my own personal 'Ethics committee' answerable first of all to myself and the respondents and then to the University of Edinburgh and Sociology as a whole. I have adhered to the Code of Ethics of the International Sociological Association (ISA). (See appendix 3 for information leaflet and consent form and appendix 4 for the code of ethics and checklist.)

5. A New Approach

As time went on and several personal events slowed my progress and gave me opportunity for reflection, I became disillusioned with the approach I had been using. The social framing of the research had shifted and more people seemed to be questioning the vaccination process than previously; sometimes with different arguments and for different reasons than before. Many more vaccines had become readily available. More people travelled to foreign countries and experienced travel

vaccinations. MMR had hit the news and possible links between vaccination and autism were circulating among parents. Some people were choosing not to vaccinate for reasons of fear of vaccine damage and issues about pollution of the body, rather than the 'life style' or philosophical/religious reasons seen before. The public was becoming much more informed. The press, the internet and people's access to alternative therapies and, therefore, various philosophies of health and illness were all playing their part in alerting people to the possibility of questioning the status quo, and thereby the playing field had altered (Saks 2005). But, most of all what made me reappraise the research was that I wasn't getting satisfactory answers to my questions about how and why people make the decision not to vaccinate. In consultation with my supervisor it was suggested that I attend some lecture in medical anthropology to help untie some of the mental knots I had created for myself. Subsequently, studying and attending lectures in Anthropology helped to refocus and reignite my passion for this study. As I learned more about social research, about anthropology and about feminist research I became once more aware that there was a great need for my research and that I had a responsibility to do this work as stated by Lietz:

"There is an ethical responsibility within social work to uncover voices that have been hindered or to bring awareness to perspectives that have been oppressed" (Lietz 2006).

I felt this ethical responsibility very strongly, and it has been my intention with this research to bring awareness and validity to the voice of the non vaccinator.

6. Finding My Voice – Theoretical Orientation

I suppose I had a minor identity crisis of some kind. To write like a sociologist or anthropologist I would have to feel like one, and I didn't yet. My difficulties with finding a theoretical orientation were partly to do with my lack of knowledge, my confusion with the language of medical sociology, and perhaps also with the academic approach itself. I could not see at the time, how academic work would lend itself to doing research with the purpose of giving a voice to the non-vaccinators. There were times when I felt 'tainted' by my research topic and felt somewhat ostracised by fellow students - somewhat similar to what my respondents said they also felt when the subject of not vaccinating came up in their community. I had issues with some of the concepts which feature in some of the more traditional sociological literature, for instance; the idea of 'categories' of people in the more positivistic sociology. The people I interviewed did not fall easily into a sociological category, they didn't live in one place, they all came from different backgrounds, and they had wide ranging professions and life-styles. I was much more interested in how people were all different than how they might be the same or fit into certain types or groups. Another sociological concept I found difficult to accept was the concept of "risk" within sociology. The vaccination questions are frequently framed around risk, both for health practitioners and for patients. If you don't believe in vaccination then the issue of 'risk' becomes diffused. Not all of my respondents were 'non-believers' however, so it was an issue for some and I have explored 'risk' in the previous chapter as it is an important concept in sociology generally.

I looked at vaccination in terms of religion, philosophy and history to find a way of framing my research that felt acceptable and justifiable to me. In the end,

with the help of my supervisor and further reading I found a way through to the present. What was always foremost in my mind were the people I had interviewed and that they needed a more public and respected, or listened to voice than they were getting. In order to be able to do justice to the respondents and the subject, the method of research would need to delve into the philosophical orientation, the ‘why and how’, of the respondents and attempt to show how this is often not understood or accepted by the health establishment and the public. To achieve this it was important to let go of questions as far as possible in order to get to a narrative of their experience via their words, not my questions. The relevance and the strength of this research would be all the better the more the respondents could feel themselves empowered to tell the story of their lived experience rather than feeling that they were the objects of my study (Esterberg 2002).

I would also like to think that my work may have some influence, however small, on the future of medical sociology, thereby giving me and my respondents a voice within academia, as stated by Agger:

“What and how students write has an effect not only on their career, such as where and what they publish, but it has an effect on the discipline, which is reproduced and potentially redirected through the next generations of sociology” (Agger 2002:346).

The respondents and I collaborated, co-constructed, created this work with a purpose, a positive aim, with a will to improving understanding between people and improving children’s health and wellbeing.

7. Recruiting, Gatekeepers and Respondents

Although I interviewed 30 people in all, I only used 15 of the interviews for this thesis. I didn’t use the ones undertaken with people with whom I had had some

previous history, or who knew of me in my homeopathic capacity. Also, some of the interviews were technically unsatisfactory and couldn't be transcribed. (See also appendix 2a.). The 15 respondents interviewed for this MPhil research project were recruited from a variety of sources. An element of "purposeful sampling", in which *"particular settings, person or events are deliberately selected for the important information they can provide that cannot be obtained as well from other choices"* (Patton 1990:169),

has been utilised. Five came from a direct appeal to other homeopaths on the Society of Homeopaths internal intranet service, for willing patients from their practices.

The interested homeopaths asked their patients to make contact with me by email, letter or telephone if they wanted to take part in the research.

I also contacted the following professional organisations because I was aware of their views regarding vaccinations: The Informed Parent, JABS, Scottish Autism Society, a private school, two Chiropractors, three Medical Herbalists, Christian Scientists, Scientologists, Orthodox Jews, Mormons, Muslim Medical Association, and several others. I had useful conversations with most of the representatives of these organisations although not with all of them.

The most fruitful source of respondents came via the homeopaths and The Informed Parent organisation. Of the total 15 interviews, seven were members of the Informed Parent organisation (four of these were also patients of homeopaths), one was a herbal medicine student, one was an infant teacher, one was a parent from a primary school in Edinburgh, three were patients of homeopaths in the south of England and two were grown-up children of homeopaths, one of whom was also a parent.

I was met with some suspicion by some of the people from religious organisations when approaching them. They didn't seem to trust me. As Richard Mitchell noted in the Loflands' book (Lofland and Lofland 1995:35):

“Qualitative investigators...may seek to present themselves in one manner or another..., but subjects can and usually do reinterpret, transform, or sometimes altogether reject these presentations in favour of their own. During his 2-year research sojourn to acutely segregated South Africa in the early 1960s van den Berghe attempted to act, according to the dictates of his conscience, as if race was of no consequence. This behaviour was accounted for in a variety of ways by the South Africans. He was viewed by whites as a Communist agitator, an odd foreigner who had not yet learned to “handle the natives” (van den Berghe, 1967 p189), or as merely socially inept. Blacks classified his behaviour as that of a police informer, agent provocateur, missionary do-gooder, or paternalist (van den Berghe, 1967, p 190) Virtually no one, White or Black, understood his actions as expressions of the non- materialistic Gandhian socialism to which he was personally committed” (Mitchell 1993:12).

Although this quote may seem unrelated because of the setting, in many ways it is very much about the same dilemmas, prejudices, misunderstandings and misconceptions that I also encountered in my work when speaking to some potential gate keepers, health professionals and academics.

I would have liked to have pursued these contacts further, but it takes time and I already had enough respondents and had done 30 interviews already. I learned something about the importance of gate keepers and also about my own sensitised status within the organisations where I did have instant access and easy rapport, namely those organisations and groups of people who have traditionally used homeopaths for their health care and those that include mothers who make decisions independent of the NHS or Government. The Loflands also mention this;

“It seems quite typical for outside researchers to gain access to settings or persons through contacts they have already established” (Lofland and Lofland 1995:37).

Gaining access to respondents is a privilege and needs to be earned and/or learned.

Thought and time needs to be devoted to this task. The advantage of being an outsider as opposed to being an insider is debatable, as either position will greatly influence the research outcome, whatever method is employed. In some ways I was lucky in knowing the key people of the organisations I used and knowing how they communicated with their members.

“Gaining entry to a setting or getting permission to do an interview is greatly expedited if you have connections” (Lofland and Lofland 1995:35).

This became clear to me very quickly when making enquiries about possible recruits. I do think that the ease with which I recruited these respondents had a direct effect on the outcome of the research, even though the respondents were for the most part not aware of my profession and my connections with the organisation in question.

Vaccination can be a very volatile subject as indicated by the in excess of two million web pages that come up in a Google web search for ‘vaccination dangers’. I did find some of them very instructive and informative and many have influenced my respondents also. (Jones 2005; Kim 2006)

Several homeopathic practitioners and two medical doctors also put themselves forward for the project. I did interview them but then decided not to include them in this study, because their language and thinking was too professional and they were not talking from their own experience as parents, but were preaching or teaching. They could give me knowledge, but I wanted understanding of the problems engendered by ‘not’ vaccinating from a parent’s point of view.

Once people had responded positively that they wanted to be part of this study I sent out the research leaflet and consent form, either by post or email as they

preferred (See Appendix 4). They then signed the consent form and returned it by post. I then telephoned or emailed them to set up an appointment for the interview. The length of the interviews varied from 45 minutes to 2½ hours.

All the interviews were recorded with a digital recorder. I personally transcribed them all. For me, the transcribing, although tremendously tedious in some ways, gave me the opportunity to really get to know the material. It also gave me the opportunity to listen to myself and gain some degree of reflexivity with the whole process (Mauthner *et al.* 1998). It was a mistake to collect interviews and not transcribe them immediately, which I also tried to do to save time. On the occasions where the interviews were not recorded properly, field notes and some useful phrases and memos had been noted down, so not all was lost.

Ten of the interviews were conducted by telephone and directly recorded. Two were done face to face in the home of the interviewee, and three face to face in my office. (See Table 1, next page). As can be seen from Table 1, most respondents were women, only two men were interviewed. Both these men were partners of women who were also interviewed. Given that the caring role of women in the family makes them the main negotiators in health matters, women were the face of the decision, even though some of the men also had opinions on the subject. Graham also mentions that women are the...:

... “interface between the family and state’ and frequently makes them the ‘go-between linking the informal health care system with the formal” (Graham 1985).

Though I am obviously not the ‘state’ I was still an outsider and the research will have been seen as a formal event, as a paper had to be signed and recording permission granted.

Table 1 The Respondents

	Pseudonym	Age range	# of Children	Where they live	Profession	Child Vac status
1	Martha	40-50	1	Scotland	Alternative health care practitioner	None
2	Amanda	20-30	2	Scotland	Herbalist	None
3	Jessica	20-30	1	SW England	Marketing	None
4	James	20-30	1	SW England	Biologist	None
5	Astrid	40-50	2	S England	Alternative health care practitioner	Some first child only
6	Ruth	20-30	3	Cornwall	Full time Mother	None
7	Hugh	30-40	1	SE England	Graphic designer	None
8	Pam	30-40	1	Midlands	Biochemist	None
9	Celia	30-40	0	Africa	Archaeologist	None
10	Helen	20-30	1	Bath	Arts editor	None
11	Jennie	30-40	2	London	Editor	None
12	Karen	40-50	4	Scotland	Early childhood education	Tetanus only
13	Morag	30-40	2	Scotland	Environmentalist	Tetanus and DPT
14	Melanie	20-30	1	London	Writer	None
15	Jane	30-40	2	SE England	Business	None

Although several fathers responded initially, when it came down to who took the actual responsibility for making the final decision about vaccination in the family it was always the mother, in this research, who had the final say. One father, a single parent, put himself forward, but when it came to organising the interview, he made it very difficult and pulled out, due to “lack of time”.

8. Interviews and Fieldwork

The respondents had made some very difficult choices in their lives as parents and several said that they had experienced abuse from health professionals, family members and strangers, for making what was in their own eyes, a positive choice in the best interest of their child. From my previous work with non-vaccinators I was well aware of many of the arguments for and against vaccination. What I was now looking for was not so much *what* these arguments were, but *how* they related to real life situations and the experiences of people within the context of their daily lives and contact with the health service, and what lay behind their decision as philosophy or view of life. This places my work more into the arena of constructivist critical theory and feminist theory. As Denzin explains:

“Feminist theory and thought is restructuring qualitative research practices. From them are coming new ethical and epistemological criteria for evaluating research. At the same time, these perspectives are making lived experience central to qualitative inquiry and developing criteria of evaluation based on ethics of caring, personal responsibility, and open dialogue” (Denzin *et al.* 1998:1982).

Some of the research projects and writings which informed and inspired me during this time were of a feminist and supportive nature such as (Cunningham-Burley 1990; Miles 1991; Roberts 1992; Oakley 1993; Doyle 1995) and some others.

There are many ways of interviewing people; ways of asking and ways of listening. I attempted to use a variety of positions in the different interviews to ascertain the effects on the experience of interviewing and on the quality of the material collected. By using a more supportive way of listening and questioning I was much more likely to gain the trust of my respondents and thereby gain access to their truth (Finch 1984).

Only two respondents were interested in who was funding my research, they questioned my motive; to be able to say that I was self funding made communication much easier with these respondents as they knew that I wasn't funded by the pharmaceutical industry or the public health system whose agendas they distrusted. The fact that I was paying to do this research made them realise my tremendous interest in the subject and perhaps made them more generous with their own thoughts, experiences and words and of course their time. That I was also a parent who had had to wrestle with the vaccination issue for the sake of my own children did also help to gain their trust (Oakley 1981). In this sense:

"the personal is related to the ethical, the moral, and the political stand point" (Clifford 1998:243).

The respondents were very obviously interested in my research, they contacted me voluntarily, there was no reward for taking part, and they gave generously of their time to be interviewed. Like Janet Finch says:

"Almost all the women in my two studies seemed to lack the opportunities to engage collectively with other women in ways which they would find supportive and therefore they welcomed the opportunity to try to make sense of some of the contradictions in their lives in the presence of a sympathetic listener" (Finch 1984:138)

They wanted to talk about their experiences; they wanted validation for their decisions and their parenting skills. They wanted the world to hear their story but had not been given a valid voice.

The way I introduced the interview with my latter respondents was rather different to the earlier ones. Instead of asking, "What made you decide not to vaccinate your child?" I asked, "Would you like to tell me a little about your experiences around vaccination and non-vaccination?" (See Appendix 5) This

changed the stage from one where the respondent felt the need to protect themselves and argue for their choice to a much more intimate and supportive approach of listening to their personal experience. With this kind of approach I was much more likely to open the flood gates and gather several pages of insightful narrative.

Mishler argues that many forms of research interview suppress stories either by ‘training’ the interviewee to limit answers to short statements, or by interrupting narratives when they do occur (Elliot 2005).

Mason explains it very well:

“Our ways of seeing, and of framing questions, are strongly influenced by the methods we have at our disposal, because the way we see, shapes what we can see, and what we think we can ask. In that sense, researchers can fail to appreciate how methods driven are their questions. Of course, as a consequence of the way researchers are trained and tend to operate in disciplinary settings, very few individuals are conversant or competent with a wide palette of interdisciplinary methods, or those spanning quantitative and qualitative demarcations. This means that research questions may tend towards conservatism, and social scientists may repeatedly miss whole dimensions of social experience because their methodological repertoire or tradition limits their view” (Mason 2006).

I don’t believe that the problems experienced by ‘professional social researchers’ artificial focus, that Mason talks about, has necessarily been an issue for me with my later interviews. Not because I am a particularly experienced researcher but because as a somewhat older person I have inhabited various professions and life situations: as a daughter, as a parent, a company director, as a clinic manager and as a practitioner, a friend, a mother, a member of staff, a student, a teacher, an orchestra member, a choir member, a boss, and quite a few more. All these have their own ontology and ways of relating to others and have had some influence on my skills as an interviewer or listener. Two of the respondents asked me if I had children and if they’d been vaccinated. Sharing my own personal experiences in this case made it

much easier for them to share their stories (this may also have created other problems around assumptions). Finch also spoke about the instant rapport created by revealing something about yourself:

“The consequences of doing so can be quite dramatic” (Finch 1984:142).

Perhaps the ‘gatekeepers’ had also had a very positive effect on the ease with which people responded and came forward with their stories and dilemmas. They knew about some of my work as a health care practitioner and writer and perhaps saw that my aims were supportive of their aims.

In the process of transcribing the recorded interviews some analysis took place and subsequent interviews were more useful, longer and more nuanced. I was happier with them, they were freer, more open, I said less each time and I was able to learn to phrase questions and interjections in such a way as to encourage longer passages of uninterrupted narrative and not “force” the direction of the interview (Glaser, B 1992). Although definite questions were helpful in some instances to get someone talking, I learned that often a subtle ‘Mhmmh↑’ or ‘Yeh ↓’ response kept a person more focussed on their own story while at the same time letting them know I was listening and supporting them if that is what they seemed to want, or urging them to continue. This did help to distance myself from the respondent’s stories, to help me to be less emotionally involved and thereby have a more professional objective academic ear. This does not mean that I didn’t hear their emotions, or acknowledge them, I just didn’t respond to their emotions in an emotional way.

My way of speaking and asking was relatively informal and friendly. I also made it clear that I didn't have any ulterior motive, apart from carrying out research and getting a degree.

9. The Respondents and the Interview

On the whole it was probably the more self educated and vocal of the non vaccinators who put themselves forward for this project. Sometimes I was amazed by the amount of knowledge acquired and study undertaken in medical science by the respondents with the purpose of empowering them to make this difficult decision.

I hope that the respondents also gained from being part of this research. They were all people who took an active responsibility for their own and their families' health care and well-being, model parents in many respects. Parents who make positive pro-active decisions for the better health of their families based on research. By taking part in the project the respondents were able to clarify their own thoughts and explore questions they might not even have known they had. Elliot tells us how this comes about:

“The interview therefore becomes a site for the production of data and an opportunity to explore the meaning of the research topic for the respondent” (Elliot 2005:65).

They were also all people who had problems with some of the elements inherent in bio-medicine; elements often labelled as: dualistic, mechanistic, reductionist, empirical and interventionist (Hardey 1998). To them these are not acceptable paradigms for understanding and explaining the experiences they encounter as principal health carers for their families.

There was also an element of us working together to help alert the world to their reality; that non vaccination is not a stupid, irresponsible or selfish thing to do. This may put the research into a:

“stream of evolutionist and interventionist work, where “subjects” are seen as partners in the research process” (Punch 2005:18).

Together we (I and the respondent) want to look after their children’s wellbeing and in some cases also improve on the health service provided by the state. Here they are not seen as subjects, but as:

“respondents, participants, stakeholders, in a constructivist paradigm that is based on avoidance of harm, fully informed consent, and the need for privacy and confidentiality” (Punch 1998:38).

As the researcher, I found myself in a rather dichotomous position of having to be both open and honest with them and of being objective and reflective at the same time. This did create a dilemma or tension. The best way I found of dealing with this was to try to say less and listen more. The respondents very much wanted to tell their stories. They are in a position within society where they cannot often discuss their position. Some said they had been accused by health professionals, family members and even strangers of being a ‘bad mother’ or a ‘bad citizen’. They may well feel the need to explain themselves to someone who will understand and validate their choices, someone who will not judge them or be frightened or feel threatened by their opinions. Their explanations were complex and multi faceted and often revealed an underlying world view or philosophy of life more in keeping with alternative medicine (Sharma 1992; Weston 1992; Lupton 1994).

By giving the respondents more freedom in choosing the direction of the interview I am consciously, but indirectly, asking them about their experience rather than attempting to validate my own.

Although I was quite sure how I was going to go about the process of analysing the data, grounding it in theory took longer to work out. There are many theories and books on the subject of methods with different approaches and orientations.

In the end I used a qualitative constructionist approach somewhat influenced by feminist sociology for the interviewing. Although vaccinations aren't mandatory in the UK, it has become an accepted practice, and anyone choosing not to have vaccinations for themselves or their children may be seen as 'different' or even 'misguided'. This made the participants of the project somewhat vulnerable and some of the principles underlying feminist research seemed to be the best way of dealing with the controversial and emotionally charged issues surrounding childhood vaccination (Renzetti 1993). I chose a feminist way of listening to my clients (Oakley 1993). The researchers using the feminist approach seemed to me to be a little more supportive of their subjects and also often seemed to have an empowering agenda, which seemed particularly appropriate as a number of my respondents had felt severely criticised and bullied for their health beliefs in the past.

The research and analysis process was not always straight forward or easy. Just as the respondents' experiences weren't straight forward or easy either. Their stories were complex with some having a vaccination one time only for an arbitrary reason and then never having any others. They might believe in some vaccinations and not others or they would vaccinate in some situations and not others, or they

vaccinated their older children but then changed their thinking and didn't their younger ones. Because of the complexity of people's experience, a narrative approach was seen as the most desirable and effective tool to use to give the respondents their own voice and to limit manipulation of the data by the researcher (Elliot 2005). How this is done is explained by Graham thus:

"The narrator knows she is providing information; the story marks out the territory in which intrusion is tolerated, and thereby sets limits on the possibility of manipulation and exploitation which haunts social research" (Graham 1984:68).

By allowing the respondents to use their own words, by not giving them my questions to answer, I gathered better data for analysing and therefore the issues that were addressed were their issues and not necessarily mine.

The aim of this study was to explore non vaccinators' health beliefs; not from the point of view of increasing vaccination uptake, or to find out how best to reassure them about the safety of vaccination, but to hear their voice so as to better understand their point of view and their choices. The respondents were people with a variety of health beliefs and behaviours, including several who had vaccinated in the past but changed their minds later, one who did sometimes vaccinate when she was persuaded to do so (as she said) and another two who told me they weren't sure if they would vaccinate in the future or not. Some had good experiences with health professionals; most had many vaccinating friends and family. By doing in-depth interviews with such a varied group I felt I was able to produce a nuanced analysis of these people's views and experiences. They were not a homogenous group in opposition to both biomedical practice and pro vaccinating parents, but individuals with complex stories from their varied lives.

10. Analysing the Data

Once I felt that I was happy with my interviewing methods, I practiced various ways of listening and questioning; occasionally even within the same interview. In this way an analysis was ongoing and method was somewhat fluid.

After I had decided that I had enough interviews and was thinking about how to go about making a whole out of the parts, something quite interesting occurred; I suddenly had the experience that the material had a life of its own somehow. The stories of individuals took on a unity and I began to be able to interact with the narrative and to understand the life world of these parents with all their tribulations, their searching for the right/best options for their children and their decision making processes.

I coded the individual interviews for emergent themes; the themes then became categories in which multiple similar experiences could be placed. There were rather too many themes and some could be discarded as they overlapped, or became irrelevant.

I then took folders and titled them with a sticker with a theme written on. I cut out the relevant theme from each transcript, wrote the name of the person who'd said it on the back and stuck it into the relevant folder. I did it like that so that I could carry the whole lot with me and work on it on train journeys, at home elsewhere. I did this with each theme and with all transcripts. Sometimes I had to rearrange things a bit as there were too many in one or not enough in another. At first I really didn't like cutting into the transcripts as I felt that I was ruining a wholeness that someone had given me. But this was an essential part of analysing and after a while I enjoyed seeing what Jessica said, or Amanda or Hugh, and how

things were the same and how they were different. Once I had the final categories, these also were classifiable into chapters of a story. I was quite astonished about the whole process of grounded theory. Intellectually it didn't make a great deal of sense to me initially, but in practice it had a reality to it and I began to understand and appreciate it more as time went on.

The respondents separate stories fell into place in my mind like a complex single coherent story almost as soon as a point of saturation in terms of new themes had been reached. At the same time I spent a lot of time looking at taking individual quotes from the respondents' narratives and analysing them, creating at least three different framings for each quote. What does she say here? What does she mean? What does it say about her experience (this was sometimes psychological, sometimes biographical). I also drew maps about that. I did what felt right, ethical and logical to me. That this is called grounded theory and is post modern in approach became clearer as I began to understand the literature about methods.

Grounded theory methods were used to analyze the data. (Glaser 1967,1977,1992; Strauss and Corbin 1998; Barbour 2006) were all very helpful in developing the methodology. It took me quite a while to get an idea of what grounded theory actually is and how it works. It wasn't till I studied Charmaz's latest book that I began to feel some confidence in my understanding of the method. This may be due to this book in particular as it is very comprehensive and clearly set out, or it may have been a cumulative building up of knowledge and understanding from all the reading I did on the subject and her book was one of the last and most up to date when I read it. Instead of embracing the study of a single process or core category as in Strauss' and Corbin's approach, Charmaz assumes diverse local worlds and

multiple realities and aims to show the complicities and complexities of the particular worlds, views, and actions. Constructivist grounded theory, according to Charmaz (Charmaz 2006), lies squarely in the interpretive tradition of qualitative research with flexible guidelines, a focus on theory that depends on the researcher's view; learning about the experience within embedded hidden networks, situations, and relationships; and making visible hierarchies of power, communication and opportunity. She places more emphasis on individuals' views, values, beliefs, feelings, assumptions, and ideologies than on research methods, although she does describe the gathering of rich data, coding the data, memoing, and using theoretical sampling and all the usual research grounded theory tools also. After having read Charmaz, grounded theory began to make sense to me because by moving the interpretive post modernist and post constructivist paradigms into grounded theory she brought it up to date. Post modern scholarship involves us in:

'the ontological politics of staying true to complexity' (Denzin and Lincoln 1998:36). Which was my aim also.

All the main aspects of grounded theory such as: coding, memoing, diagramming, framing and situational work were used in an attempt to be true to post modern scholarship ideals. I developed a list of core criteria and processes from the interviews which then developed into new categories. These new categories were then used as codes to create a flow or story of ideas. I made maps with the ideas. I cut out all the coded bits of text from the interviews and placed them into marked envelopes, as mentioned before, which I then sorted into a cohesive story for the analyses chapters of this thesis. No computer analysis program was used, as manual

cutting and pasting using paper and scissors, although laborious, was deemed to be sufficient and perhaps more oversee-able and flexible.

Placing myself, the researcher, as the participants' cohort in this research process, rather than as an objective investigator of their experience, was vital to a constructivist grounded theory design. This was done using a myriad of minor methods, for example: the recruiting via their own small organisations of which they felt ownership meant I was a visitor in their territory, and, by adjusting my attitude, my tone of voice, my responses and my questions during the interviews to suit each individual's personal stories and to be supportive of these stories as valid stories meant I was there with them.

Reflexivity was a constant companion during the research process. This was made real by memoing and keeping a journal and writing down my experience of each interview and thinking as it happened.

I purposefully included my voice in the writing up of the research both because it felt more truthful to do so and because it is recommended by both Charmaz and Mitchell (Mitchell 1993; Charmaz 2007). I was not a silent data gatherer but by listening, recording and writing I was co-creator of the data.

The shift in sociology from modern to post modern society, according to Jan Pakulski, is demonstrated by the shift in the focus of society on productivity to a focus on consumption (Pakulski 2009). This is demonstrated by the respondents in their experience of themselves as wanting choice in vaccination, wanting to be health promotion consumers rather than health intervention recipients. They experience themselves as complex individuals with responsibilities and choices to make about

their own and their family's welfare rather than citizens at the receiving end of government policy.

Strengths, weaknesses and rigour.

The aim of this research was to explore the health beliefs held and practices undertaken by a sample of parents who have chosen to reject vaccination, either all or some of the time, for their children or themselves.

By listening to the stories of each individual's experiences surrounding vaccination immunisation one to one, I was able to hear and record a wide variety of narratives, thoughts and feelings on the subject in depth. The respondents were drawn from a wide age range, geographical distribution, and vaccination history, country of birth, profession, education and number of children and comprised both sexes. The most obvious factor these parents had in common was that they had decided not to accept a vaccination at one time or another for their child, or themselves. The in-depth approach, using their language and saying little myself helped to facilitate expression of the broad range of experiences and preserve, as much as is possible, of the complexity of these respondents' life world.

The fact that I didn't interview people who did vaccinate their children with all immunisations offered, means that I cannot compare the responses of these two groups. I have tried not to make assumptions in my analyses and discussion about possible differences between these two groups, and have referred to findings on others' research on vaccinators and listened to those in my own respondent group who did vaccinate sometimes. In this way, I have been able to provide a detailed account of the experiences of those who participated in my study but obviously not of other parents.

By only using 15 of the respondents' narratives, the influence of one or two of the more vociferous and politically charged respondents of the group could perhaps have weighted the findings somewhat in their favour. I have avoided this in my analysis by making sure that all respondents' accounts have informed the themes presented. However, the accounts of those more strident respondents also bring to the fore the polarisation engendered in society by this subject itself, something that was experienced by many of my respondents but reflected less overtly in their accounts.

That the interviewees were by and large well educated middle class people may have been a limitation of the study. Though I didn't recruit them for that attribute, and, although I do not want to generalise beyond my sample, others' research in the field of parents and vaccinations had similar findings. I do therefore think that their social class is a relevant wider point.

The size of the study was small but, because I felt that I had reached a point of saturation in terms of new ideas during the last few interviews, using fifteen interviewees is a reasonable number.

The fact that I recruited from groups of people, who are supportive of CAM therapies, could also be seen as a weakness or a limitation. It was, however, the most obvious source for recruiting non vaccinators, so the decision was a pragmatic one. Again, by not generalising or making assumptions about how different they might be, I hope my analysis can partially overcome that bias.

The respondents usually knew that I was not from the NHS, because of the way I was introduced to them and because of my qualifications. This also had implications, both positive and negative. It affected the way they felt they were able

to talk about their NHS health professionals to me. It was in that respect a 'safer environment' perhaps. In one case it meant that one of the respondents used the interview as an opportunity for a bit of a rant, a letting off of steam. Since they usually knew that I wasn't from the NHS they may have thought that there wasn't any way that my research would improve their relationships and their experiences with mainstream healthcare practitioners; this may have put a negative slant on their narrative, and exacerbated the aura of despondency and division present in some of the narrative. But, perhaps that is also part of the research outcome.

Summary

From my preliminary work as a practitioner to reorientation and development as a researcher was harder and took longer than anticipated. The world of sociological research and academia is complex and has many faces and approaches. I found its complexity sometimes confusing and even disheartening at times. There was a time that I felt that the more I learned the less confident I became about my knowledge. That there are multiple realities and conflicting theories within sociology could perhaps be seen as encouraging, as it is true to life. It demonstrates that people are individuals and are striving for cognition and understanding, and demonstrates that society inhabits multiple and complex networks of reality. As this project was primarily a process of learning about research, the length of time it took and the amount of study undertaken to accomplish the research was perhaps unnecessarily large and long, but it did mean I could obtain rich narratives and study them in their complexity. And, rather than the project being a snapshot of the experience of not vaccinating at one particular point in time, it has elements of the

changes in the understanding of vaccination over a time span by the individuals in the study, and the beliefs and actions associated with their health related decisions for themselves and their children.

The next three chapters form the analyses chapters where some of the research findings are revealed and explored. From exploring how they made what was, for most of them, a difficult decision, to what or who influenced them and what they thought about vaccinations is discussed in chapter 4. Then in chapter 5 how their children's non vaccination affected them and their children and their community is shown. What do they mean by 'healthy' and what measures do they put in place in their family life to keep healthy, ending with their view on what makes a non vaccinated child different from a vaccinated child. In chapter 6, the last analyses chapter, some of the important underlying themes instrumental to their decision making and their understanding of how health works are exposed and explored. And finally, concepts such as medicalisation, the politics of health care and power as it related to these respondents are also looked at.

Analysis chapters 4, 5 & 6

Chapter 4. Making a Difficult Decision

Introduction.

In this chapter, I will look at what influenced people to make the decision not to vaccinate either their children or themselves. The people involved in this research all made a conscious and informed choice not to do so. They were all articulate, responsible, well informed people who decided to make this choice with various degrees of confidence and conviction. Some were strident supporters of the anti-vaccine lobby and angry at the government for promoting what they saw as a dangerous and damaging intervention of the health and well-being of their children. Others were more subtle and protective of their privacy and only wanted to live their own life in their own way without being persuaded into a practice they understood would be harming their children. Still others were disheartened by the commercialisation of the world and in the, as they saw it, manipulation by pharmaceutical companies of government health service policies. Then there were those who weren't sure about the issues and opted not to vaccinate to be on the safe side, keeping their options open. That this is a complex decision making process and that health beliefs play a critical role in the decision has been shown in other studies also (Hobson-West 2004; Smailbegovic 2003; Alderson 1997; Leach 2007). In this chapter I will share some of the main issues and difficulties the respondents encountered in making their decisions about the health care of their children; and what, or who, influenced them to make what may seem to many, a radical choice. In Section 1 the focus is on self-determination and a 'common-sense' approach to decision making. How they made their decision and what gave them the confidence

to be so individualistic is explored. The way they discussed and incorporate concepts of immunity into their decision making is discussed next. The section ends with a look at how intuition and wisdom empowered the respondents to self-determination and freedom from convention. Section 2 explores the outside influences on their decision making. What people told me about ‘who’ and ‘what’ influenced them. Section 3 delves into the concepts and philosophies of health and illness that the respondents discovered they held while exploring and researching the vaccination debate and how these ideas did not fit in to the generally accepted ways of doing things.

Section 1. Self determination

a. “Common Sense”

Amongst the respondents there were those who saw the accepted medical intervention of vaccination, particularly MMR, as unnecessary and irrelevant, because their own personal experience of the illnesses had not been serious when they had them:

Jessica: “We also both had, as children, some of the diseases that they immunize against and not had any problems. For instance, I’ve had mumps and either chicken pox or measles, I can’t remember which one it was. And James (husband) had mumps, and we knew people who had various diseases and were fine. We thought, well, if we were in a third world country where perhaps, where perhaps these diseases would cause infections and we didn’t have proper medical care if we did get ill and things like that, it would be a completely different scenario. But, as it is, if Sara (baby) does get measles or chicken pox she’ll probably be, you know, she’ll be, she’ll have good nutrition, she’ll have very good healthcare and, you know, chances are she’ll be absolutely fine with them. So we are actually not that worried (laughs) about her getting the diseases themselves.”

She didn’t doubt the validity of vaccination as a process; she believed that it might work, that it did what it was meant to do. But she felt that it was inappropriate in her situation. She thought that their own relatively high standard of living and the

benign environment she and her partner (James) felt able to create for their family made vaccinating their baby unnecessary. This was not an unusual point of view with the people I interviewed as borne out in other studies also (Smailbegovic *et al.* 2003). Both she and her partner, although they had different views on some aspects of the subject, both came to similar conclusions when it came to deciding about the relevance of vaccinations for the third world, or poor economic environments.

James: *"I think that hygiene counts for a lot of it. In the third world if you don't have high levels of clean water then vaccinations may be more cost effective. Vaccinations are easier to supply than clean water, and you can charge for them easier. This could be a short term fix. This, if it is true, is rather damning."*

James is perhaps criticizing the lack of foresight and the lack of generosity of third world health providers and their links, economical and political with vaccine suppliers. He also implies that clean water may be the solution to many of the ills of the third world as it was for us in the west in the past.

And another:

Jenny: *"From reading and research and my own experience of having minor childhood illnesses I don't think there is anything wrong with people living in a clean healthy environment in the western world, getting mumps, for example. But then, if I was in Ethiopia and my baby was going to get Diphtheria from somewhere and there was a chance that being vaccinated would change their life, they wouldn't die, then I would think completely differently about it."*

Jenny also believes that vaccinations probably work, but that childhood illnesses are not dangerous in our western society and that vaccinations are therefore a waste of time, money and effort.

These respondents believed in vaccinations for the third world, but not for themselves in the west.

The idea of “common sense” as the respondents named it, when deciding on whether to have vaccination or not, or using logic, played a large part in informing the respondents rejection of having a vaccination for themselves as well as for their children. Sometimes vaccinations really were not necessary at all, they thought, even though there was quite a lot of pressure to have them.

Jessica: “Again, when I went to Zimbabwe and Mozambique there was a possibility of having to take anti-malarials and we chatted to people I was going to be working with and they said, well it’s winter now, mosquitoes aren’t out in the winter and we are quite high up in the hills and there aren’t that many mosquitoes where we are, so although the whole travel advice for the whole country was: “Yes, it is a malarial zone”, in fact the travel advice for the exact place I was going to be was, “Well, the mosquitoes aren’t around actually”. So again I was able to not have them.”

Although the above quote relates to travel vaccinations and malaria in particular, it does bring up some very important issues about the necessity for some vaccinations or some interventions which are prescribed or suggested when they are in fact irrelevant to the case. It shows that vaccinations have become a kind of panacea for safety. When going on holiday people buy their travel vaccinations in the same way that they buy travel insurance or travellers cheques.

Celia: “When I went to the doctor to ask whether I should have anti- malarials for going on a dig to Israel, she was so weird. What she said was that I had to have them, that if I didn’t take them, I would be bringing Malaria back into the country and causing a danger to others. Now, I don’t really know that much about vaccinations, but that to me just sounded so ridiculous and impossible, I never went back to that doctor, and I didn’t take any anti-malarials either.”

As an archaeology graduate student she knew enough about malaria to know that it wasn’t infectious, you can’t catch it from someone else, so she totally lost faith in that doctor and couldn’t bring herself to ever go back to her for help or advice.

b. Concepts of Immunity – the immune system

The immune system as a concept is central to the vaccination debate and was an important feature in the interviews. Working with the concept ‘immune system’ in the health care arena is a relatively new event.

“The concept of an immune system as a system of interacting parts, an all encompassing framework, has existed in science only since the 1970s.”(Martin 1994:3)

Though frequently used to help explain health and illness, the phrase “the immune system” as a complete body system with all its complexity involving interrelated organs and systems, is still far from understood. Vaccinations and the science behind them predate what knowledge we now have of the workings of the immune system. The more scientifically minded respondents that I interviewed believed that the science behind vaccinations did not take the interrelatedness of the immune system into consideration, thereby invalidating the logic for vaccinating. The respondents though, not all knowledgeable about the scientific explanations underpinning the concept of the immune system, seemed to have taken to the idea of the immune system, perhaps because it empowers them. It is something they can do something about themselves without having to resort to complicated biochemical scientific language. There is ‘wholeness’ to the concept of immunity and an idea of protection (Martin 1994). Some respondents talked about the immune system as if it were some kind of great protector in the body. The majority of the respondents said that a healthy immune system was something their babies were born with, something which needed protecting and nourishing, not by others, not with drugs or surgery, but with good nutrition, sound lifestyle decisions and loving care. If a healthy immune system is at the foundation of good health, then they, the parents hold the key to its

integrity. The concept of the immune system empowers people, especially mothers and carers, to look after their responsibilities. One of the most frequently purchased OTC herbal remedy for instance, Echinacea, is marketed as an 'immune booster' (Percival 2000). Homeopathy is often described as acting directly on the immune system or enhancing the immune system function. All the above concepts are made visible in this quote:

Jessica: *"I feel I am protecting her by not having her vaccinated. I want to strengthen her own immune system, which is designed to protect her. With, you know, being very careful about what she eats. Organic food wherever possible and a nice balanced diet, you know, all sorts of things that will help her be healthy, you know. And she has, so far, been incredibly healthy. You can't really say why, or what she would have been otherwise. I mean medical intervention is a wonderful thing where it is needed and it can help. I'm not in the school of thought to never touch any medical drugs in any circumstances. If I was in a car accident and needed a blood transfusion I would have one. I'm not at that end of the scale. But as a preventative thing, good general overall health is much more desirable and probably more effective than medical intervention when it isn't needed."*

Jessica views vaccinations as undesirable because she sees them as an unnecessary intervention. She also believes that she can make a difference to her child's health by taking responsibility and by making conscious and carefully planned choices about her everyday life. She thinks that medical intervention i.e. vaccinations, are detrimental to her child's health. She is quite humble in her assertions and doesn't rationalize her decisions. Her partner supports what she says:

James: *"I guess part of it is a gut feeling, she eats very healthily; she has a strong natural immunity. There is also a suggestion that if you don't vaccinate a child and you leave her to fight off illnesses herself you give her the opportunity to develop her own natural immunity and her ability to fight new foreign bodies and so I'm quite interested in that. I would much rather give her the ability to build up her own immune system. For me our decision to not have her vaccinated isn't the end, we may change our mind later."*

Both Jessica and James used the words "I am protecting her" but in a completely opposite way from the way a GP or health visitor would use the phrase. The bio-

medical view is that vaccinations protect the person from illness, where the non-vaccinator would understand that they are protecting the child's immune system from harm by not interfering with it with vaccines. The primary care health professionals do not yet seem to include the immune system in the equation when promoting vaccination. To the parents I interviewed, it seemed that the health professional who attempted to persuade them to vaccinate, were not really interested in their child, but rather in statistics. Many of the respondents said they believed that by allowing a child to develop natural immunity, by having access to the natural disease, they would acquire a lifelong immunity. They found this preferable to what they termed partial/temporary immunity", as acquired by vaccinations, which they see as harmful and not desirable. So both Jessica and James said that by not vaccinating they are protecting their child from harm. Jessica's mother is a homeopath and although she made up her own mind about vaccinations, she was sensitized to the issues surrounding vaccinations before she became pregnant. When I asked James how he first became aware of the issues and if he had problems with the decision himself, he said that he trusts Jessica because she has done all the research and she makes the decisions about all things health in their family. Whenever he talked about decisions regarding vaccinations he always said "we", where Jessica said "I", which shows perhaps who has the final say in the matter. I also asked them if there was a difference between deciding for themselves or their child, if it was different.

Question: *"So that's the experience for yourself, but you've now got a child as well so that kind of...what's that like?"*

Answer: *"Mm, it's an interesting one because prior to coming over here (he is from New Zealand) it was always: 'Which vaccinations do we need to have?' Whereas with Sara (child) it is more: 'Why does she need it?' It is a different way of thinking and we are beginning to question these things a bit more."*

c. Wisdom of the body and intuition

Many of the respondents shared the idea that the body has inherent wisdom. This is more of a religious/philosophical concept which is perhaps not always taken seriously by science and therefore by those health professionals who rely solely on science for the grounding of their own beliefs. This wisdom intuitively feels that the body is all wise because it is essentially divine. The confidence that such a belief engendered was quite remarkable and made the decision not to vaccinate much easier for those respondents who did hold such beliefs (see Jessica, Amanda, Karen). Present-day UK society doesn't readily allow for the open expression of spiritual concepts, in fact it has become almost a taboo to mention the word 'Divine' or 'God' or 'Spiritual' without a proffered apology of some kind. The fact that people hardly mention it doesn't mean the underlying concepts aren't there.

Amanda: *"I don't believe in vaccinations I certainly don't feel they would be less healthy not having them. So why bombard them with vaccinations? Then, so I have been quite happy with that decision for about 8 months, then I started getting other mothers and my mother in law questioning that decision. That made me start questioning whether I was doing the right thing or not? Because I couldn't actually back up my argument with research because I hadn't actually read any, I had just done it on instinct"*.

Often called the 'emotional response' in the literature, 'instinct' as a part of this decision making process, came up in other research also (Sporton, 2001).

Helen: *"Firstly for a young baby only 8 weeks old to be injected with all those drugs is wrong."*

Those who are in touch with an "inner truth" where they "know" that they are making the "right" decision by not vaccinating often can't articulate it in rational terms. They may just say that they felt it was "wrong".

"Scientific proof might appease others, but it is not necessary to their self-confidence. Nor is it necessary to ensure clientele, since for many patients the question of scientific proof is equally irrelevant" (Sharma 1992).

Sharma is discussing complementary therapy practitioners and their patients in the above.

Karen: *"It was never really an issue with me that was the way it was going to be. I just knew, my conviction was such that I just knew, regardless of what I was being told by others, that I was going to stick by it."*

Her decision not to vaccinate. And also,

Jessica: *"It's more the attitude that your body is, as long as it is well looked after is capable of looking after itself pretty well. And the immune system can sort of, in normal circumstances, in normal everyday life, knows what it needs to do to keep healthy. I suppose it is more...that human beings are amazingly divine to work and we know we almost work best left to our own devices rather than interfered with in some way. I don't know if that sums it up very well really. It just seems that the more interfering we do with drugs and all the things that affect the processes that our bodies are designed to do, the more problems we are perhaps creating. The same with interventions with birth. It felt at the time very linked in with the natural birth and everything. Sara (baby) should have as little artificial man-made interference in her physical existence."*

That kind of language, which talks about, the divine or a gut feeling and an intuition powerful enough to influence such a major decision as vaccination, was not uncommon from the mothers I interviewed. It is the language of someone who listens to an inner voice which is more powerful than rationality and is perhaps not generally a voice either listened to or understood by orthodox medicine or by modern science. The philosophy and practice of many of the alternative and complementary medical professions are much more in tune with the language of this 'inner voice'. And most of the respondents consulted CAM therapists for their healthcare questions if they could afford it. It is difficult to say if it was the nature of the client to be attracted to alternative and complementary medicines or if it was their negative experience with orthodox health service practitioners that drove them to look for treatment and ideals which they could have confidence in. Both applied in different

circumstances. Wisdom and intuition have a lot more in common with alternative and complimentary therapies that bio medicine in fact Martin goes as far as to say...

'This glimpse into alternative therapies indicates to me that their goals run deeply counter to those of biomedicine' (Martin 1994:83).

The way some of the respondents talked about their relationships with their homeopaths or their anthroposophical doctor in one case (see Karen) was very different from the way relationships with their bio medical GPs were discussed. The alternative practitioner gave them the feeling that he/she was there for them only, to help the parent or child gain better health, where some parents said they felt that the GP they had consulted had other motives that had nothing to do with them or their child, to increase vaccination uptake for example or to fill quotas. This experience has been explored by other sociologists also as shown here:

'The medical profession, at best, denies women power; at worst, it reduces us to a state of passive victims. Feeling this loss of control, this passivity and powerlessness in men's hands and desperate to 'do something' about their illness (or health, my words), it is little wonder that many women turn to the complementary, fringe or holistic health care, which appear to offer women a measure of control and power over their lives' (Ribbens 1994).

It is perhaps not surprising reading the above that all of the non-vaccinators I interviewed had had some form of treatment, education or advice from either a Homeopath, a Herbalist or some other non-orthodox doctor or health professional or through reading their books.

Table 3 Not Vaccinating and birth place/style

Astrid	Martha	Morag	Amanda	Jenny	Melanie	Helen	Pam	Jane	Karen
Hospital	Home	Home	Hospital	Home	Home	Home	Home	Hospital	Home

The number of home births in the sample of respondents is unusually high, as shown in table 3. Is that perhaps because these are the kinds of people who choose to opt out of the general mass or ‘normal’ way of looking after their health? I think perhaps this is the case. Once people decide for a home birth, which also demands tremendous courage and independence of thinking, non-vaccination, alternative health care, and alternative education may follow (Edwards, 2005).

Section 2 Influences on Decision-Making

Next I will look at whom and what were the common influences on the decision making process in the respondents’ own words.

a. Influenced by Homeopath or Doctor

Karen: “When I was pregnant I read several books. One of which was by Dr Norbert Glass who was actually my school doctor. So and it was possibly because that was, I had been treated by another Anthroposophical doctor since the age of 9 and then retained that. Even when I moved away from where my Anthroposophical doctor was, she still allowed me to keep in contact. I was vaccinated; I had all the vaccinations as a child. I lived abroad, so I had quite a few. I lived in Turkey for a while. It was through the books and through my own doctor who supported me with my decision.”

Although thoroughly vaccinated herself, she nevertheless abandoned her own family orientation to vaccination and became a complete non vaccinator. She does have a vaccine damaged sibling, which she mentioned only once in passing, that may also have influenced her thinking. The fact that she feels so supported in her new found beliefs by her Anthroposophical doctors gives her the confidence to carry this belief through for the whole 28 years she has been a mother and also teacher.

And:

Melanie: *"I hadn't even thought about vaccination until 6 weeks before my son was born and he was two last week. I went to see a homeopath actually about birth remedies and she suggested I borrow a book about vaccinations; which I dutifully read. And I went 'Ooh'! Prior to that I hadn't given it a second thought. I probably had every vaccine on the planet. From the point of view that I'd done an awful lot of travelling I just never thought of it as being a problem, you know. Even myself I had Yellow Fever and Rabies, which I didn't really need to go to South America, but it was recommended as a good idea by doctors. So I'd never questioned vaccinations in my life. Then suddenly, there I was pregnant, reading this book, thinking, 'ah, well, I can't go onto auto pilot with this'."*

Her homeopath suggested she read a book which woke her up to the fact that that there were alternative options available, about which some difficult decisions would have to be made once she had given birth. That people would benefit from a 'trigger' to alert them to the up and coming vaccination decision was found by other researchers also (Sporton, 2001). Perhaps this is an area for anti-natal support to address.

Astrid: *"I have a boy who is 13 now and when he was dutifully vaccinated as a baby he quite soon developed eczema - and very bad eczema. I took him to the doctor who prescribed a steroid cream for him which at that point I was already against. I started to become a Reflexologist when he was a baby, so I started to look at things in a mind- body-spirit connection- way and how 'your body speaks your mind'. So I didn't like to use the steroid cream then because saw it as a suppression and I didn't see how you get any further with that. The eczema was terrible, it was sort of oozing on his shoulders and I was in despair. Porridge oats in his bath helped, that was a very good thing. Then a friend of mine mentioned a homeopath who didn't live too far away from where we lived, so I went to see her and Michael started to get homeopathic remedies and that was my first introduction into homeopathy. The homeopath had a workshop for parents, a First Aid course for using homeopathic remedies in the home. I went on that course and there were about ten people there and all the other women on the course hadn't had their children vaccinated. I was quite amazed and thought how idiotic I had been having done it. That was my first introduction. That was really the beginning of a different way of looking at health and lifestyle for my family. At that point Michael (her first child now 13) must have been about one and a half. Since then I have resisted the vaccinations."*

Astrid blames the vaccinations for her son's eczema. People frequently blame vaccinations for all kind of health problems with children, sometimes their hunch may prove to be right, but vaccinations do get blamed for things they aren't perhaps

directly responsible for. (I didn't have the heart to tell her, that I have treated many children with eczema who weren't in fact vaccinated, and it would have been outside of the scope of my job as researcher to do so anyway!).

A study among non-immunized children in Bath between 1987 and 1993 found that the most common reason given for their non-immunization was the use of homeopathy (Simpson *et al.* 1995). It is not clear in the article about the research if the people were using homeopathic alternatives to immunizations or were having constitutional treatment to help with their overall health and therefore felt they didn't need the vaccinations. This was not borne out by the research done in Hackney in 2002 where none of the respondents considered homeopathy to be an alternative to conventional immunization (Smailbegovic 2003:309). The difference may be due to local variations or to the fact that homeopaths had been asked to stop influencing people on this matter by the Faculty of Homeopaths (GP homeopathic association) in 2002, or it may be due to the fact that the respondents in the first study were a different group of people with easier access to homeopaths.

b. Influence of Books/Leaflets

After health professionals, the second most powerful awareness raiser for not vaccinating with the interviewees was books. Everyone had read at least one book on the subject. Here are some of the books they mentioned as being influential:(Coulter *et al.* 1985; Chaitow 1987; Curtis 1994; Gunn 1995; McTaggart 1998; Romm 2001; Sussman *et al.* 2004; Head 2005). These books vary a great deal in what they cover and in their degree of professionalism. A brief overview may provide some background:

Chaitow has been a well respected Osteopath for at least thirty years if not more. This gives him gravitas and his book is still one of the main influences especially on alternative and complimentary medical practitioners according to my own research. The book is makes a strong argument against vaccinations, is accessible and presents the arguments against vaccination very clearly. Coulter is an American pro homeopathic medical historian who writes in an academic style. Curtis, a homeopath has written this as a kind of handbook for Homeopathic Alternatives to vaccination. Donohoe is an Australian doctor, who, together with eight other professionals made a video about the dangers of vaccination which has influenced many people in the UK also as it is freely viewable on the internet. Gunn is a classical homeopath, he wrote this little book as his dissertation, but it is now out of print. Head is also a homeopath. Her book is easy to understand and very accessible to parents. It includes 5 cases with photos and five year follow-ups. MacTaggart is very well known in Britain. She is the founder/director of What Doctors Don't Tell You Ltd. This organisation published a great deal of information in a "whistle blowing" style against the established scientific medical world. She is American, a journalist and a therapist also, her style is indicative of her background, there is a lot of excellent information in her book, but many people have told me that they find her style too aggressive and journalistic. Romm is an American midwife, herbalist and mother, who speaks with authority, experience and equanimity giving both the bio-medical and the alternative view points. Schreibner is a middle European/Australian research scientist who travels the world promoting her work by lecturing and appearing as an 'expert' witness in American vaccination damage court cases. Her book and video of a lecture contains mainly scientific research outcomes;

rather inaccessible to the non scientific parent. She has put together a substantial body of scientific information about the damage vaccinations have done. She is not particularly popular with parents, mostly because she seems to be so angry all of the time and the information is so dry.

Amanda: *“Just recently I read a book, half a book; on ‘Vaccinations Yes or No?’ it’s supposed to be a balanced argument. It tells you what ingredients are in vaccinations, and you know, the statistics of how many people actually get serious problems from things like whooping cough and stuff out of the general population: it is nobody, it is nothing. But then other populations where vaccination have been less popular like Germany, they aren’t having any less problems than here. Then you see things in the press, things like, “there is going to be an epidemic”, to get people to vaccinate more. This makes me think: do vaccinations actually work? Because, everyone seems to be going from the premise that they do work. If you are not vaccinating your child you are doing it for their (the child’s) immune system or so they don’t get autism, not because they wouldn’t be protected from polio or whatever.”*

There are many strands here, not all entirely consistent. If I understand her correctly she says that in Britain very few people die from whooping cough and other illnesses they are vaccinated against. She then goes on to say that the vaccination rate in Germany is markedly lower than in Britain but the level of the disease outbreaks in Germany is no greater than in UK. This would indicate that she thinks that the vaccinations aren’t actually responsible for the control of disease. She then goes on to talk about the press and the pharmaceutical industry’s relationships with the press in using fear to influence the uptake of vaccinations in Britain. She also intimates that she is not convinced that the vaccinations work, that they prevent disease. She also wonders why so many people are content with vaccinations. She seems to have read or heard (not clear) that the reasons that people give for not vaccinating are that: a. they don’t want to damage the immune system and b. They don’t want to get side the effects. They don’t necessarily believe that vaccinations protect them from the

disease they are intended to protect them from. She suggests that perhaps many more people don't believe that they actually work than is generally assumed.

Another person on the influence of books:

Morag: *"I really tried hard to look at the information first and then make my decision. I did find some really useful books, I can't remember, something like 'Vaccinations for Parents, a Useful Guide'? Written by an Herbalist, so I expected it to be quite anti and I was surprised that at times, she wasn't at all, she was very balanced. This one book I found particularly useful because it seemed sometimes it was alright to have middle ground as well. Sometimes it is quite good not to have to be totally anti or pro something. I felt that she presented all sides. Rather than just presenting just evidence that was to back up her view, she gave both sides to then help you make up your own mind and make you own decision."*

Morag was not that confident about her decision not to vaccinate. Interviewing her was not straight forward as she seemed to be changing her mind constantly. As can be seen from Table 4 also, her children did have some of the vaccinations, when pressurized by health professionals, but she indicated that she didn't feel happy about it; it seemed she felt guilty about vaccinating. She seemed to be more influenced by the group of women she was involved with during her pregnancy, they were all non-vaccinators and she then went to the book for confirmation.

Much of the anti-vaccination literature has anarchist undertones or is blatantly against 'the system', this did often put my respondents off, because they weren't the kind of people who wanted to overthrow the system, they just wanted non-biased information which they said wasn't that easy to find.

Melanie: *"So reading more and more books, the more I read, even though the opinions I was getting were very biased, there was enough scientific evidence in them to make me think actually I can see that this information is being depressed. And I, particularly looking at vaccine theory and how vaccines work and thinking: Well if you catch disease, you are immune for life. If you have a vaccine, with a lot of them, there is a 50-70% chance they will work; then they only work for a couple of years. How can that be true immunity?"*

Another person on the NHS pro-vaccination leaflets that mention the dangers:

Answer from Jenny: *“They are what started me off on this road actually. Initially when I first started all this, I was put off by the stories of terrible initial negative reactions to the vaccines. I thought, my God, I really don’t want to subject my child to the possibility of having seizures and brain damage and have a cot death. So that emotional fear can work both ways.”*

The leaflets handed out at GP surgeries and posted by health boards came under a lot of criticism. They were found to be “trite”, “misleading”, “biased”; it was noticed that they were sometimes printed and published by drug companies who sell vaccines. Inappropriate “over-emotional language” was mentioned, this could make them feel like they were being “blackmailed” into going along with them. The language was thought to be “patronizing” and made people “uneasy and distrustful”.

Hugh: *“I found the NHS information quite trite. I would have thought it would have been more balanced, you know, saying like, this is what is for them and this is against, just more balanced. But it wasn’t at all, you know, it was more like ‘This is what happens’. Reading that, if this was the only thing I had read, you have to have them, I wouldn’t have thought there would have been any option.... There was no mention anywhere that there was another point of view”*

[To see a sample of the NHS leaflet see (NHS 2008)]

That the information given to people by the NHS was seen as biased and that information about vaccination safety was withheld has also been revealed by other studies (Evans *et al.* 2001; Sporton 2001; Smailbegovic *et al.* 2003).

c. The Internet

None of the people I interviewed said they made major healthcare decisions based only on what they read on the internet. They did all, bar one, have internet access in their home or work. The internet may have played a part in alerting them to what was happening elsewhere in the world, as Hardey says:

“The rapidly increasing use of the Internet as more people put their computers online and the creation of what has been called the ‘network society’ (Castells 1996) has enabled them, not only to have immediate access to international health

resources, but also to have direct access to knowledge that was previously inaccessible to the lay public”(Hardey 1998:45).

Very little mention was made of the internet and/or web pages by the interviewees.

Though all the support and network agencies and communities that were mentioned have a web presence which some did mention as very supportive. So with my interviewees the internet was not seen as a major source of information. The internet is perhaps most helpful when you actually know what you are looking for and can decide what is good and what is erroneous information.

d. Family and Friends

Although vaccination was not seen as an easy subject to talk about, partly because of all the emotional and political implications, eight of the respondents were first sensitized to the subject by talking about it with close friends or family.

Helen: “Like most people really, for me, vaccination was just something that everyone did. Then about 12 years ago when I was about 18 at university doing my undergrad degree and one of my flat mates, a good mate, she wasn’t vaccinated and one evening, we were just talking, I’ll never forget it, she was just ripped to pieces by my other flat mates for being irresponsible for not being vaccinated. Horrible things they said to her! I was horrified. Something that I just took for granted that everyone did. At the time I was quite interested that there was an alternative viewpoint. I tried to find out more information about it and began to be more aware of other ways of looking at it. I instantly knew that vaccination was not really the right way to go about it.”

Helen was one of the few respondents who had already been made aware that vaccinations were a difficult issue; emotionally, socially as well as scientifically, before she had to make a decision as a parent. Her words, *“I instantly knew that vaccination was not really the right way to go about it”* she ‘knew’ that vaccinations were wrong (for her), is very revealing of how some of the respondents used their own reactions, their own emotional reactions, to judge an issue, and that this happens instantly. She seemed to have made up her mind first, based on her intuitive reaction

to a stressful situation, and then went about backing the decision with references and affirmation later.

Or:

Morag: *“When I had my first child who is now 7½. I hadn’t given it any thought before that. I have been travelling a lot as an adult and have had many vaccinations you know to go to Africa, and you know, I hadn’t given it a second thought for myself and then I went to ante-natal classes at a natural birth centre, I don’t think I thought about it before that. I just talked to some of the people there a little bit and met lots of like-minded mothers in many other ways as well.”*

Morag was alerted to the fact that she had to make a decision, by a group of “like minded” women, with similar lifestyle aspirations.

Amanda: *“I know three people who haven’t vaccinated their children and they are all different. One of them has an 8 year old and she is very healthy and opinionated strong, you know, a good girl. She has never been vaccinated and her mother is very against vaccinating. Actually she has written a big dissertation on it, which I have read, where she cites how many people are filing law suits in America against the pharmaceutical companies and the amount of money involved is absolutely crazy; more than \$40 million or something.”*

Amanda was alerted to non-vaccination by several individuals who she respects.

Pam: *“I guess I was mostly influenced by my dad. My dad is very much into everything health; quite anti-government really (giggles). He always taught me to be open-minded about things that most people just assume with faith. He, he opened my eyes”.*

Pam says she is influenced by her father, who she respects as she knows he has done much private study.

Section 3 Concepts, Philosophies and Health Beliefs

The decision had been made that vaccination was not something they wanted for their children at the time of the interview. Seven were not sure that they might change their minds later, or that they wouldn't ask for a vaccination if they went to foreign places. Eight rejected the whole idea out of hand and disagreed with the whole concept of vaccination. Some of the reasons they gave for arriving at this point of view or standpoint and their health beliefs underpinning their choices are explored here.

a. Less is more

Martha: *"I don't think it is the right way to deal with the problem, you know, to inject people with illnesses in case they get illnesses. Both of us are coming from a place where we innately believe in that the human being works well if it is not interfered with. That is the principle of the Alexander technique as well really and a lot of our work as teachers is helping people letting go of interference. So to me also, to inject a body with major illnesses is quite big interference in a working mechanism. And why fix didn't really seem too difficult a decision."*

Martha questions the whole concept of vaccination. She was a great believer in the maxim "Don't fix it if it ain't broke" (which she also said). The idea of injecting her "perfect baby" with all the quite "sinister chemical cocktails" (as quoted in previous chapter) in vaccinations filled her with "horror" and seemed to her a completely wrong way to go about making, as she said, her "well" child "weller".

Morag: *"I think there is an emotive element as well, of injecting tiny babies with anything. I also rejected the heel prick you know. I also didn't want the stuff they inject you with to expel the placenta either. So I was already...I didn't want her poor little body affected by any more. I had already decided 'no thanks'. I had made up my mind that I was going to be breastfeeding anyway so..."*

Perhaps this is about medicalisation; not wanting a baby to be medicalised as well has not wanting to physically hurt a baby with a needle. All the mothers in my

research breastfed their babies – many also had home births, as mentioned before.

(See table 3).

Morag: *“I’m quite sceptical about approach the NHS has to health anyway and the treatment of symptoms rather than looking at causes”*

Morag’s quote brings up a whole new set of issues which is very important and vital to the vaccination debate-but too big to go into here.

b. Lack of Evidence – the science doesn’t add up

The respondents reiterated that there was very little evidence available that vaccinations have been properly tested. Some mentioned that they could find very little evidence, double blind trials for example, to show that they work. The science they told me, those three who were scientifically orientated, didn’t stack up. They said that their scientific questions weren’t addressed or answered.

Morag: *“...because the questions that I wanted answered aren’t, can’t be answered, no one has been able to answer them. Like the long term effect on immune systems and such. Maybe I start to become cynical. No one even looking at the development of MS! There are many unexplained developments in modern diseases, maybe they aren’t linked at all to vaccinations or they may well be linked to vaccinations but again, no one is looking at that, because nobody dares or because there is no money in looking at it or whatever.”*

The lack of available research led some respondents to distrust their doctors. Some non-vaccinators suspected that vaccinations are responsible for the major new common chronic diseases such as: MS, ME, Cancers, AIDS, Depression, mental illness. Several sounded quite angry or disheartened that no research has been done to see what the long-term effects on individuals and on populations might be.

James: *“The other interesting thing for me, coming from a science background, growing up and doing engineering or physics was always, ‘everything you told us, you have to prove it’! The government here and the government in general, doesn’t do a very good job of that. They are saying ‘do this!’ – And you have to have faith.*

Unfortunately I'm not good for 'faith' and I would much rather have cold hard facts.... "

...and about the leaflets and information the health service:

"The government guidelines on vaccinations in my opinion wouldn't receive a pass grade in first year of any university! I think that a lot of vaccines do work. I'm not questioning whether they work. I might question how effectively they work. You don't see anything saying, 'the success rate for this vaccine is...' If they are not doing double blind or anything it is very hard to test against their own criteria how a person would do without medication. In fact, when you see the graphs for the decline of illness after a vaccination (is introduced); you actually see a much more dramatic decline, before the vaccination was started. Which suggests to me that in fact it wasn't the vaccination that was responsible for the decline as much as people improving their own immunity to it."

And:

Martha: "My understanding is that there is plenty of research that shows that vaccination is not helpful. It is also my understanding that it wasn't the vaccination that made such a big difference to smallpox and other illnesses. But that information doesn't seem to be widely available."

Because the convention is to quote the source when saying something scientific,

Martha says here that it is "her understanding that it wasn't", which implies her

belief in it also. Martha doesn't like to confront people; she just wants to protect her son.

Jennie: "I don't think that vaccinations have made any difference to the health of anyone, except to make it worse. I think it is all a great hoax by the drug companies to make a lot of money and the doctors to keep us under their power. You only need to look at the graphs that show how deaths from common illnesses dropped before the vaccinations were first introduced."

Jennie views the debate very differently, she feels people are manipulated, gullible

and used by both the drug companies and the medical establishment. As a

scientifically and politically aware person she had no difficulty finding information to back her stance.

c. Catching it anyway- vaccines don't work.

Helen: *"...the research that has been done I can't find any evidence that they actually work. Then, I met this nurse, her son, when he was 19 he was going to India or somewhere and went to the travel shop and had all the vaccinations, all in one go! He got typhoid there. When he got back to England the doctors wouldn't diagnose it as typhoid because he'd had the vaccination. But in the end he went to the tropical disease hospital that did tests on him and it was typhoid. Another thing, I didn't realise till my parents came over. I always knew that I had measles as a child, but I didn't realize that I had also been vaccinated for measles. That was quite an eye opener for me."*

There were a number of incidences mentioned by the interviewees where both adults and children who had been vaccinated still contracted the illness. Another issue relating to efficacy is the question of permanence, the fact that the vaccines wear off, even after a short time, rendering the subject perhaps even more vulnerable to the disease. For instance adults catching measles because they were vaccinated in childhood when the disease might not have been as harmful. Mumps, also, is most often just a minor illness in childhood but much more serious after puberty, especially with boys.

Helen: *"Also; my friend from university, the one who wasn't vaccinated, had a blood test for German measles when she was pregnant and she was found to test positively for German measles antibodies, where my other friend, who had been vaccinated, tested negative for the antibodies. So I guessed it doesn't actually work really."*

A number of the respondents mentioned what they called the 'twisting' of statistics in promotional/educational literature on vaccinating, as a reason for not trusting them. With reference to the graphs that indicate the decline of an illness after the start of vaccinations, published in some NHS leaflets, interviewees often mentioned that such graphs are misleading because the illnesses in question had already been in serious decline for many years before the start of the vaccination program; and the vaccine, rather than being responsible for the decline, in some cases actually stimulated a slowing down of the reducing rate of infection, or even an upsurge ,

such as with polio cVDPVs (circulation vaccine derived polio viruses) (Kew *et al.* 2004). A number of my interviewees had heard that polio in particular was transferable from vaccinated babies to parents and siblings, especially via swimming pools. A survey carried out in 2003 in Hackney, London for the NHS where:

“Seven children from the same community had not received polio vaccine” also bears this out. *“Their parents stated that someone within their community had contracted polio from the vaccine”* (Smailbegovic, 2003:304).

Hugh: *“I was quite impressed by the information from my studies that the childhood illnesses were on the way out anyway through improvement in general hygiene, uhm, diet and whatever improvement in people environment and living habits. And that claims are made for the success of vaccinations when they probably weren’t actually greatly responsible. And thinking, well, are we just sort of comforting ourselves with the thought of vaccination that we are sort of protected when actually they are not, it actually too big a leap of faith to not do it, to not vaccinate.”*

Hugh expresses his observations on faith and medicine.

d. Vaccine Damage

Vaccines wear off, viruses mutate, vaccines may very well be toxic, and they certainly do contain many toxic substances. There are many cases of anaphylactic reactions to vaccinations which is a frightening prospect for many parents. One of the respondents, who worked with special needs people in the past, did mention this:

Karen: *“It was understood in our community that many of the people there were vaccine damaged.”*

That some health professionals know about the dangers of vaccinating but carry it out anyway, probably because it is health policy, is borne out by the following:

Pam: *“I mean my brother, who is two years younger than me, he was actually, well he was suffering from febrile convulsions when he was a baby and the doctors and nurses then, actually they said not to have him vaccinated with the whooping cough vaccine because it could make matters worse.”*

The proliferation of allergies in this day and age, and the increases in the numbers of people with atopic syndrome, often expressed as asthma or eczema is frequently blamed on vaccination by non-vaccinators and some others also.

Pam: *“You know, I’m allergic to Guinea pigs. That came out of the blue when I was ten years old. I would love to know if it was the vaccination that made me that way.”*

Is she implying that because part of the vaccine was attenuated in Guinea pigs and that some of the Guinea pig proteins or other parts have been injected into her body along with the vaccine causing her allergy problem?

The fact that there is a comprehensive vaccination compensation scheme is also a factor in alerting parents that vaccinations are not without danger. Why would there be a compensation scheme if the vaccines are meant to be safe?

I did not focus on vaccine damage in my research and therefore did not pursue interviewing parents of vaccine damaged children.

e. Pollution and Toxins

In the last ten years, the consciousness of pollution, whether environmental or personal and the “detox” revolution has grown substantially. With all the organic food programmes on television and proliferation of organic cosmetics and natural fibres in clothes, the extra taxes on gas guzzling automobiles and the ‘carbon footprint’ slogans on every bill board and magazine; it is not surprising that the idea of the chemical pollution with vaccines has been an issue for many parents.

Morag: *“Nobody is looking at the combined effect of chemicals that are all around us in plastics, medicines and all that sort of thing and vaccinations.”*

Morag, as environmentalist, sees vaccination as a foreign chemical in the body, a poison, so she concentrates on the pollution aspect of vaccinations.

Melanie: *"It is like a poison. It's like it's a poison that we're injecting into their tiny tiny bodies. And the fact that the dosage is the same for a 3 month old or a 5 year old I can't get my head 'round that. You know, my background, I've got a master's degree in mechanical engineering, I'm logical, very evidence based. Basic mathematics, you look at the weight of a 5 year old, you look at the weight of a 12 week old, how can they possibly be needing the same amount. If they can get that wrong... (laughter) how can I trust the rest of what they say."*

Melanie, also science trained, questions the lack of individuation for each person, as a major flaw in vaccination provision. Vaccinations are not logical, so are not truly scientifically prescribed, so are not valid.

Karen: *"All my four children are actually very healthy). And aside from anything else, I don't particularly want to put something into their body that I have no idea what it's going to do, aside from anything else."*

Karen finds that there is not enough evidence to prove that the vaccines are safe or to explain what they do in the long run. She'd rather do nothing in case she harms her children.

Amanda: *"So I haven't vaccinated her. Having read the research about, for instance, the mercury in MMR, uhm that doesn't appeal at all. I remember in class learning about people who had syphilis in the 17th and 18th centuries, treating themselves with mercury, all their teeth falling out and them going mad. And the Mad Hatters' with their top hats with mercury in them and that mad Chinese emperor who ate balls of mercury and went completely crazy. Well obviously it is not the same amount of mercury but mercury is toxic".*

That mercury was used as a preservative in the MMR vaccine is well established.

Although this has now been replaced with something else, nevertheless the memory lingers and trust has been damaged.

Summary

That women in particular are responsible for the health of their families (Stacey 1988), now well established knowledge in sociology, and was very obvious in this project also. Though the respondents stories were often complex, their

feelings and opinions were clear and made sense. The most clearly defined reasons given for not vaccinating were reasons based on their belief systems; theirs was fundamentally different from the belief system underpinning the NHS. What was most important to all of them was that they did not want to harm their children with vaccinations and they wanted to protect the purity/integrity of their children's (or their own), immune systems. They said that they didn't believe the literature or the medical profession who promoted the vaccinations. The science-orientated respondents in particular didn't find the evidence convincing. These findings often placed them in difficult circumstances where they felt they had to undertake many months of rigorous and challenging research in order to come to some understanding of the science behind vaccination and to find the evidence that would support their own internally derived views on vaccination. They are challenging science.

Jonathan Gabe has done some work on these issues and talks in these terms:

“where the power, status and knowledge of the medical profession, for so long virtually taken for granted, is being challenged from both inside and outside the health care system”(Gabe 1995:124).

In some ways these people may well be the product of the DHSS 1977 policy to encourage self-responsibility when it comes to health care combined with,

“disillusionment with the record and the prospects of curative medicine” (Allsop 1984).

And also perhaps,

“a culture of anti professionalism within which doctors were characterized as more controlling than caring” (Zola 1972).

The tone of the interviews was on occasion very sympathetic towards health professionals, more in the genre of being sorry for them, that they were misguided

and tied into a system where they had no choice but to follow the party line. The pharmaceutical industry however, with their million dollar business plan, was viewed with much more cynicism and suspicion. The relationship between government, bio-medicine and the pharmaceutical industry also came under attack, and will be discussed in the following chapter.

Chapter 5. Non-Vaccinators: Relationships & Experiences.

Introduction.

Being a non-vaccinator had implications for everyone involved; parents, children, their family and friends and all people they came into contact with, their associated health professionals, the pharmaceutical industry and also society as a whole, now and in the future. This chapter examines the point of view of the parents of unvaccinated children who had been vaccinated themselves in the past and also one parent who hadn't had any vaccinations herself. The points of view and experiences of the wider community do also have a part to play in the dialogues between myself and the respondents in as much as they have influenced the stories.

In section 1 of this chapter parents' experiences of communicating or keeping silent about their choice are explored. The variation in their degree of confidence and contentedness with their decision is looked at. Some parents expressed anxiety about their decision. One talked about 'guilt' as being a prominent feature in her family where her brother has autism, which her mother believes was the result of vaccine damage (long before the MMR debate). A few of the interviewees suffered loneliness and exclusion which had some bearing on their and their families' life. For some there were implications for their relationships with their doctor or nurse due to their choice not to vaccinate. Section 2 looks at the un-vaccinated child; how they are perceived as healthier and/or different by the respondents. What 'healthy' means for the respondents and how this differs from the idea 'healthy' within the bio-medical model. They also told me about the effect of their non-vaccination status on their experiences with other children and at school. All the parents

expressed their ideas about health care options and what they did to keep their families healthy.

Section 1 Experiences of Non-vaccinating Parents.

a. Fear of disease vs fear of vaccination, anxiety.

That the subject of vaccination was beset with emotional undercurrents was borne out by the stories the respondents told me.

Helen: *“When I was at university one person in the dorm died with meningitis and everyone wanted the meningitis jab then. The fear experience is very strong with vaccination.”*

Fear of disease is perhaps the main driver for those who go ahead and have the vaccinations for themselves and their children (Leach, 2007). This fear of disease also affected the non-vaccinators I interviewed. With them this fear was somehow countermanded. They managed to bring into balance the fear of disease by both a fear of the vaccinations themselves and a faith in the ability of the body to keep itself well and their own capability as parents, particularly mothers, to nurture and protect their offspring and keep them well.

Morag: *“It is at times like that where it is felt like a big weight. Occasionally I wake up in the middle of the night and have a think about it.”*

Anxiety about their decision, whether or not they did the right thing, affected most of the respondents to some degree. This was most common with their first child and within the first year. There was an increased comfort with their decision over time and with subsequent children.

b. Family issues

Some of the people had encountered difficult situations which divided the family such as:

Helen: *“My family is an interesting one. They are very open-minded. When I told my mother, she was not surprised at all. With my husband’s family it is very different. He comes from a medical background, his father is a pharmacist and his grandfather is a GP and his mother is a radiographer. They were quite horrified to find that I questioned the system and the doctors.”*

Pam: *“Mother-in-law and sister-in-law are really anti what I’m doing. But they will never confront me about it. They have a go at poor Peter (her partner), who hasn’t read everything I’ve read. So it really is unfair and I wish that they would come to me. They know that I’ve got the answers but they don’t want to hear them from me. It was very difficult for my husband, the pressures put on him by the whole family.”*

Both Helen and Pam experienced a rift between them and their partners’ families caused by their own stance on vaccination. The unvaccinated child him/herself can also be angry when grown up when they discover that they have been made to be ‘different’ by their parent’s non-vaccination standpoint.

Karen: *“It is quite interesting that Erica (her eldest child) when she was 17 when she went to Ghana, so she had to have lots of vaccinations for that and I mean I remember her reaction to me; “Why didn’t you do all these”? (Angry and critical tone of voice) But now she is studying journalism at university and that is actually one of the questions that came up. The lecturer actually said, ‘Well, nobody here doesn’t have vaccinations!’ She was able to stand up and say that she hadn’t been (till going to Ghana). Because she had attacked me so much and wanted to know why I hadn’t done it, we talked about it for hours; she was then able to bring that there. She was quite pleased then.”*

Another family showed more tolerance to the decision;

Morag: *“My mother is fine. She has a, what I consider to be a really common sense approach to such things. Also she remembers me having measles, and though it wasn’t particularly nice for me, it wasn’t a big deal. Lots of other children had measles at the same time, so she thinks it has, what she calls, ‘It has gone too far’. Then again with my sister having done it, I don’t think she has particularly questioned her either.”*

Researcher: *“What about your sister, does she know you haven’t vaccinated then?”*

Morag: *“We haven’t talked about it. I haven’t really had an in-depth conversation with her for years now.”*

The words *“It has gone too far”* in the above quotation, highlights the thoughts that a number of respondents voiced, this was particularly true of grandparents I spoke to

or people slightly removed from the immediate vaccinee in my earlier exploratory work, the idea that there are too many vaccines now. There was a general consensus that with polio or smallpox, there was a place for mass vaccination, but now, for minor childhood illness from which we all recovered fine in the 50's 60's and 70's and 80's, there is no need for such a mass vaccination scheme.

One way of dealing with the variety of opinions within families was, to not discuss it. This did seem to mean that sometimes people within a family avoided each other while their children were young and of vaccination age. Avoiding each other seemed to be the most usual way of avoiding confrontation, fear and guilt. The following quotation illustrates what happened in one family when the truth came out about not being vaccinated.

Martha: "My sister who has two children the oldest one is just a little younger than Jamie and has developmental delay problems. So he is coming up to five but he is more like a two or three year old in his development and she has more recently had a little girl who was born about nine months ago and she doesn't want my son to see his little cousin. Because she is afraid. She is afraid; I didn't even know she knew that Jamie wasn't vaccinated because it is not something you bring up is it. But she brought this up for me that she didn't want Jamie around Lucy because he wasn't vaccinated and she has so much fear having had a child, who, not only has had developmental problems but also has been ill, been seriously ill from time to time and been hospitalised and she has such fear around that. Because of her viewpoint she sees an unvaccinated child as a danger. I'm glad I didn't have to meet that a number of years back. Partly I feel sorry for Jamie. I have hardly mentioned his cousin. He knows she is there; we even had a big family wedding. My brother got married and the way they parent anyway is very different, the little girl is in a car seat the whole time. So it was easy she wasn't being passed around people you know. When we approached her to say hello, she took the baby away to the car and left her there. But he (Jamie) would love to have held her, the way he held my friend Karen's baby. He wasn't able to touch or get near his cousin. So we haven't ever seen them really which is sad."

According to Martha, her sister seemed to think that Jamie (Martha's son), by not being vaccinated, was somehow infectious and should be kept away from her baby. By her attitude, the sister implies that being vaccinated will make a child acceptable

to be associated with, safer to come into contact with. A non- vaccinated child is a wild child, a dangerous child, to be avoided, in case they infect her own vaccinated child. This attitude most likely driven by fear of disease is so illogical; it must be part of much bigger picture, a picture about the social norm and the process of normalisation. There is another instance of this kind of thinking in my interviews which I will go into more deeply in the next chapter. Normalisation as a scientific concept is being looked at also within bio medicine, as people begin to question why there are so many medical interventions.

“The Normalisation Process Model is a theoretical model that assists in explaining the processes by which complex interventions become routinely embedded in health care practice. It offers a framework for process evaluation and also for comparative studies of complex interventions. It focuses on the factors that promote or inhibit the routine embedding of complex interventions in health care practice intervention” (May 2007:267).

c. Keeping Quiet

Generally the respondents said that in their experience most people they came into contact with avoided discussing vaccinations, with some exceptions.

Helen: *“Now, two years ago when I was pregnant I attended antenatal classes with a group of about 12 women where we discussed childbirth related things, such as foetal monitoring, research and vaccination. So I was surprised that the other mothers didn’t have opinions about vaccination as it seemed such an important issue to me.”*

Discussing vaccinations, even in a closed group such as a childbirth class, proved very difficult or just didn’t happen for most respondents. When asking more about why this might be, some of the respondents told me:

Melanie: *“It’s because...we did talk about it and the reaction we got was very strong because as soon as you say you are not vaccinating, you therefore imply, whether you like it or not, that they have made the wrong decision. And, in fact, most, all of those who go with the flow have vaccinated, one for the MMR did single jabs privately. But it is just simply something that is not discussed. It is almost like*

an unspoken agreement between us all that we are the rebels and they'll keep talking to us as long as we don't mention it [vaccinations]."

By mentioning that she didn't vaccinate, or didn't intend to vaccinate her child, she was inadvertently criticising the "normal" choice, she was somehow accusing those that didn't have a personal view, those that went with the status quo and vaccinated, that they were being negligent. It assumes that she is implying that they were putting their child's health at risk, and that she, because she had studied the consequences of vaccination herself was somehow better or knew better than them. This could make her very unpopular with her peers, so the best way to avoid such a confrontation was to say nothing.

Jessica: *"I told a couple of people that I wasn't vaccinating and it's interesting it doesn't get discussed as much as other things. You know, we are always talking about how our babies sleep and what they eat and all that kind of stuff but the vaccination thing doesn't come up quite so much."*

When I asked Jessica if she would discuss the topic with her friends or acquaintances in the future she told me:

Jessica: *"With close friends I would, and if somebody asked me I would. All my friends know that that is what my Mom does and that she has these special sessions for new parents and I talk about it quite a lot. (Her mother is a homeopath) But, I suppose it was at a time when I was just making new friends with people with small babies, none of the close friends that I knew before have children, only one or two. With the people I was just meeting, I didn't think I knew them that well and I didn't know sort of what their attitudes and beliefs might be, so I didn't. Because it happens when your baby is so small, I hadn't really met many moms at that stage, certainly nobody where I felt you know I knew well enough to go into anything that personal. But, I think with my close friends in the future when they have kids I probably would at least I would certainly bring up the fact that there is a choice."*

That the topic of vaccination is deemed to be more 'personal' as she says, than the food they eat, or childbirth, or breastfeeding, shows how tied up with our belief systems, our concepts of ourselves and our individuality the subject has become.

Choices in feeding babies and in childbirth can also be very tied up with feelings of

guilt, shame and belief (Edwards 2005; Kitzinger 2006, 2007) although perhaps less so now than in the recent past.

Jessica seemed very confident with her decision not to vaccinate and with her skills as a parent and was very articulate and able to express herself very well. Astrid was much less confident to go out and influence others and had come to her decision later in life, her first child was vaccinated. But she was very confident about her decision for her own family as she experienced the improvements to her and her children's health through her changes in lifestyle.

Astrid: "I don't talk to people about it very often because I can't remember all the facts and figures. I also don't want to have discussions like that because I don't see it like that."

Astrid doesn't see the argument for or against in terms of facts and figures. She made her decision at the same time as changing her life generally, becoming "life-style" oriented. She mentioned the phrase 'to let your body speak your mind' (see previous chapter) which is a term used in Emotional Freedom Technique and some other CAM therapies, to signify the interrelatedness of the mind and body, and the importance of the mind in healing (Flint 2001). For Astrid the decision not to vaccinate was much more about self development, of mind centeredness and not about medicine or social responsibility.

Hugh: "People don't sort of talk about it. You know everyone talks about their children what they're doing, how they are growing, what they are eating, that sort of thing. But it seemed quite, I don't know, sort of judgemental to say that I'm not vaccinating. You are sort of; it really is a very personal subject. Yes, people get very defensive; because it is in a way, very difficult to justify vaccination as well if you stopped and looked at it."

Hugh doesn't talk about vaccinations to others because he doesn't want to embarrass someone into seeing that they have made a wrong decision, or a decision they cannot

justify. He also doesn't want to look as if he is suggesting that he is better than others by having made the right choice where they have made the wrong one.

Melanie: *"In our area there are quite a few people who I would say are educated middle class and I know there are a lot of us not getting our children vaccinated but never telling anyone."*

Melanie has brought up something that has occurred to a number of the people I interviewed, the problem of incorrect statistics. One of the respondents who hadn't had her children vaccinated, had asked to see her children's medical files and noticed that on the file they were down as having had the vaccinations, when in fact they had not had them. I asked her what she did about it. She told me "nothing", as she didn't want to embarrass the practice. The falsifying of surgery records to raise the vaccination levels within a community maybe a much more common occurrence than is realised and could significantly distort vaccination statistics; it would indicate that a lot more people are vaccinated than actually are.

James: *"My colleague at work, he's got a little boy who is two I think and I know he's had his vaccinations but it was only mentioned in passing, we didn't, there was no sort of chat about it at all. Oh, I only kind of picked it up because he was off work in the morning to take his son to a doctor's appointment. I did kind of start to say that we were thinking about perhaps not doing the whole thing, but couldn't discuss it further as it felt like such a personal thing. It's funny though isn't it, because you can talk about poos and all kind of things, their first step or whatever, but not that."*

James doesn't feel that work is a suitable place to discuss such very personal things as vaccination as it is too confrontational. By telling someone who may believe in vaccination that you are not doing it, you may antagonise them or may make them think that you are calling them a bad parent, or perhaps leave yourself open to being accused of the same.

Pam: *"It was very hard in the beginning and then I joined the Informed Parents and that was great. I got a list of people in my area that I could contact, who thought the same as me."*

For someone who has different health beliefs finding like minded people to discuss things with can be empowering and comforting (Nystrom 2004).

d. Guilt in the family

There were also comments about feelings of guilt in the family regarding having had a child vaccinated who became autistic afterwards. I didn't interview vaccine damaged children's parents, for reasons discussed in the previous chapter, but the stories of vaccine damage do affect everyone and 'guilt' associated with allowing a child to have a vaccination that consequently may have been the cause of damage did filter through to a sibling and to the next generation.

Pam: *"And they feel guilty now. My brother is slightly autistic and they feel very guilty. But no one knew about that at the time."*

She is talking about the possible connection between vaccination and autism here.

The subject of guilt was never blamed on not having vaccinations. Guilt was only mentioned in relation to having had a child vaccinated and then being responsible for any harm this might cause. Two of the respondents, where older siblings were vaccinated and younger ones weren't, mentioned that they felt guilt and sadness about the impossibility of undoing the vaccinations with their elder children, *"before I knew better"* (Astrid).

e. On Vaccinations and schools

Several parents who had school age children, or had spoken to people who had children in school, were upset about the social implications when vaccinations were introduced at school. They felt that the information given to children during the lessons for instance was inappropriate because the other side of the argument wasn't presented. Administering vaccinations in schools, was in their eyes completely

inappropriate and made their life and their child's life difficult as it singled them out to be "*abnormal, deviant and disease carriers*" (Morris 2005:48).

Pam discussing a friend's child: "*The poor child came home from school and said, 'Mummy, measles is a terrible disease and it's coming, and if I don't get the vaccination I could get it too'. And, to do that to a child! The mother is so upset!*"

She felt strongly that this kind of indoctrination was inappropriate for an educational establishment as it was exclusive, divisive and discriminatory.

Here Astrid talks about alternative approaches to first aid at school and vaccinations suggested for a school trip:

Astrid: "*When my son went away on a school trip in year 5, all his friends were standing in a long queue, giving them medicine, they all had inhalers they all had headache tablets, God knows what else. And Billy (son) had Arnica in case he hurt himself, the cream and the tablets. Also they were supposed to have an injection of Tetanus, which Billy didn't have. I was just about to go ahead with it when they were somehow referring to the notes and they said, 'Oh, this is Tetanus and something else'! I then talked to my homeopath about it. I then came back to the doctor and said that I did want him to have the Tetanus, but not the others. So they couldn't give him the Tetanus because they didn't have it on its own. I was very worried about it and sent away to several organisations for papers about Tetanus vaccinations and after reading them I was very glad that he hadn't had it.*"

Had tetanus been available singly, she might have let her son have it.

Pam: "*What they teach them in school, like about doctors and nurses and I said (to her child), 'Well, we don't go to doctors do we?' I don't know, I get pretty fed up with the school itself and putting all that stuff into their brains. Like vaccinations are essential and this and that and the other. I don't know, in state education they do that. It is very confusing for her. It's like I have to tell him the teacher is wrong or lying or something*".

Children can become stigmatised and ostracised by being seen to be too different and may have to experience other parent's fear that they might be disease carriers.

"Both the labelling process and the label itself can have enduring consequences for the child and can limit the life-achieving potential of the child" (Mason 2000:148)

It can occur that vaccinations are given at school; as has happened in many districts with the Rubella vaccine and now again with new cervical cancer vaccination which

came out in September 08. This makes the whole process of either vaccinating or not vaccinating a completely public process.

Melanie: *"I would happily keep him off school for a week if I knew that this would prevent that happening."*

Keeping them off school for the duration of the vaccinations and perhaps for a short time after as well, in case the vaccinated children may be infectious, was the only option for many parents, if they are to protect their children from scrutiny, stigmatisation or perhaps even from disease.

Martha: *"It is one of the reasons why we have decided to home educate."*

That some people decide that they have no option but to home educate because they feel that their children's health maybe at risk of vaccination at school may not be mentioned as a reason for removing a child from school as it may be too complicated to explain.

f. On Being Different

Vaccination is not something that happens naturally by itself, it is an intervention by the state via the health service. If a mother didn't go to the hospital for childbirth, the alternative would be to give birth at home. If she didn't bottle feed, she would most likely be breast-feeding her baby. But with vaccinations, the alternative is not to have the vaccinations at all, which is not only different but is the opposite of vaccinating. So by not vaccinating, the parent may be viewed to be opposing the status quo and indirectly questioning the behaviour of those people who did have their children vaccinated. This has made life, for some non vaccinating parents, sociologically more complicated. In some cases it has made parents feel

isolated and different. There are many parents who go for the single-vaccine option rather than the multiple jab as the only option offered by the NHS, but none of my interviewees fell into that category, although two of them did contemplate that option.

Pam: *"I don't like being singled out. I just keep quiet."*

Astrid: *"I don't know anyone really down here who thinks like me, so I am a bit on my own here."*

Martha: *"I have a different view point than the rest of my family."*

Although it was not expressed by all the respondents, confusion, anxiety and fear about their choice was for some an all too frequent companion during the first few months or sometimes years of their life as a new parent. One of the parents in particular felt quite a lot of anxiety.

Morag: *"I think that somewhere along the line I was influenced, and someone else I knew who had a child had got it in hospital (the condition Meningitis). I knew one child who had had it, you know you hear about it as well, so I think it was circumstantial as well that it was a little bit of a panic, and it was a new vaccination out. You could have it on its own. I think that also influenced my decision. Also with the HIB one, they, I read about it, that if you haven't had the injection by two or something, they are quite likely to have got their own immunity. So I was kind of hoping for the best on that one. Then another kind of Meningitis came along and I thought, 'Well, I better do that one'. I find it very confusing. I go through periods of confusion and less confusion and more clarity and less clarity or whatever. I did also, anytime I've nearly done it again, I think about all the other things about vaccinations and that's usually enough to stop me again. Thinking about preservatives and heavy metals, if that is what is used as a preservative. It sounds like they are being sort of gradually removed at least some of them but..."*

The NHS literature presented to new parents caused quite a lot of anxiety also:

Morag: *"I think it is because you know, you get packs of information, all about cot death and meningitis and things that make me go slightly neurotic for a while. I was horribly overanxious for three months when Millie (daughter) was a baby, where I wasn't with Steve (son). A lot of that was down to the material that..."*

There are many stories around about what is and what is not safe; no one seemed to have the definitive answer. The respondents felt they couldn't very well ask their doctor, because they went against their advice in the first place.

Jessica: *"The only place where I thought it may have been an issue was at the swimming pool funnily enough. Because I said, 'How old does she have to be to take her swimming?' One receptionist said 'Oh four months so that she's had all her jabs.' I then asked a few other people, one said that swimming in the pool with an unvaccinated child was never safe, because of the possibility of catching polio. And then I phoned up the health visitor and she said there were no restrictions at all. So I took her swimming when she was two weeks old and it was completely fine. But I was quite scared about it."*

There have been so many myths and rumours about this issue, and stories about adults contracting polio from changing babies' nappies, no one knows the definitive answer, least of all swimming pool staff, who should perhaps have some knowledge on the issue of safety in their own pool.

Martha: *"We don't go to the swimming pool. I am a bit sorry about that. But I'm not sure about the polio being in the water from newly vaccinated children."*

g. Interactions with health professionals

How the respondents handled their GP's, practice nurse's or health visitor's attempts to persuade them to vaccinate their children, varied enormously. The people I interviewed had good relationships with professionals on the whole, with a few exceptions.

Martha: *"They've never put pressure on me. She brought it up and we had a wee bit of a discussion and obviously she looked serious but probably just realised that I was coming from a place and felt strongly about it. You know, they already knew that I'd had a homebirth with an independent midwife so that I was coming from a place that was different than their norm and all of that. So no doubt that was in my records. I didn't have scans either, I don't know if that is in my records but that was a strange thing for them as well. But it was like she gave me a wee bit of a 'spiel' because she thought she was coming from a strong place and she had to give this 'spiel', but I must have said something like...I don't remember what I said. But she gave me a disclaimer form that I was more than happy to sign just to say that I had been offered them and that I was choosing this and I was more than happy to do that. There are*

pressures and fine they are doing their job. But other than that it has been fine. I never went along to the health clinic visits that much. I went to the standard checks and the six week and even those, I always felt a little bit....I remember Jamie coming out of the last one, I think when he was 4, and saying, "Why did I have to go to that?" I found myself saying, "I'm not really very sure?" It seemed good at the time but..."

A supportive health-visitor was very much valued by one respondent:

Jessica: "The health visitor who came around when baby was about a week or ten days old was also supportive actually. She wrote in our sort of, you know you get this uhm red book, health record, and she wrote in it how we preferred to use homeopathic medicines at present and you know made sure that it went through on our record in various places so that we wouldn't keep getting bothered."

Not everyone had such a supportive experience with their health visitor however:

Karen: "I had the whole health visitor thing initially, but this particular health visitor was also a parent and I had been at school with her which kind of made it easier. But I do remember her saying to me at a later date that she had been warned about me, so she trod very carefully. I did think that was rather interesting that I was labelled. I remember very clearly, when they were both very young, and I felt very vulnerable as a mother and I felt very judged and criticised as a mother and was literally told that I was a bad mother for not having them vaccinated. Which really upset me very much."

The criticisms and condemnations a number of the interviewees said they endured from health practitioners who perhaps felt themselves to be in positions of power, had the effect of alienating them even more. Accusations such as: 'being a bad mother', 'being irresponsible', 'putting your child's life at risk' and 'you don't know what you're talking about', were mentioned.

Melanie: "You will never win against a doctor who has been coached by a drug company and everybody else; they will always have an answer up their sleeve. But I felt at least I need to be able to prove that I'm not being irresponsible. So far that has been enough. Just to get them to shut up and make their final winging comment as they go away."

Harsh words from Melanie. And more:

Melanie: "So I started asking questions of the health visitor. Usually they got very aggressive. Saying they'd seen what had happened to children who'd had measles, they'd seen what had happened to children who had all the different illnesses that they'd need to be vaccinated against. And that I was being an irresponsible mother

if I thought I was going to put him at risk of those diseases. I remember even asking them, 'But I've had measles, my husband had mumps, I've had a lot of these and I'm fine.' To which she said, 'Well, statistically you're the lucky one. Children get very ill and some of them die! So they basically painted a picture of diseases as being out and out killers, even though I remember them as completely normal childhood diseases that I had years ago, that no one really had problems with unless they were already quite ill'.

Melanie sees the childhood illnesses as benign events, from her own experience.

Astrid: "When we moved away from London, when the first child was two, we kept being bombarded with letters that said, 'Your child hasn't had his preschool booster, will you please come in', and I kept ringing in saying, 'He's not having it, I am convinced'. And at the end I got pretty fed up with all the harassment, it's not like they actually cared, they were only losing money weren't they. But in that town there were a few other mothers I got to know. So when I had my second child at that point I said, 'If I'm going to have anything to do with any health visitor I want someone who will understand my views. I got a very nice lady who didn't even question it. So I haven't had any extra letters saying, 'Sam (second child) hasn't been vaccinated why is that?' Since we've moved down to Dorset just a year and a half ago, no one has questioned it; we haven't even been to the doctor here."

Negative experiences with health professionals concerning vaccinations were more likely to occur in circumstances of stress and anxiety and where the relationship was not permanent such as with hospital consultants or an out of hours GP.

Pam: "When he first became ill, we didn't worry so much at the start but then we did and we took him to the doctor. That was a horrendous experience with that doctor. He was absolutely terrible. He was blaming me; it was my fault that Billy was ill. He said, 'It's probably measles'. Well, he had no spots. He looked inside his mouth and his tongue was coated white. 'Are they Koplick spots then?' I asked. He said, 'Yes' (brusquely). They weren't. It wasn't measles. He listened to his chest and told me it was clear! He had Pneumonia! It was far from clear! This guy was basing it on pure prejudice. No science behind it all. He was very aggressive with me. He blamed me, for not having vaccinated my child! He wanted to have this long blaming conversation in front of my ill child when it had absolutely nothing to do with it. I mean even if I'd poured boiling water all over this child I wouldn't expect a doctor to stand there and blame me like that. It made me feel awful."

And talking about what happened a year later:

Pam: "The doctor I've got now, she asked me about it. She talked about measles. I said, 'To be honest with you, I would be more worried about atypical measles because of pulmonary involvement.' She said, 'Oh oh oh oh, we are more worried about central nervous system involvement' (mimicking stressed doctor). So she thought, 'Well I can't argue with this lady!' She said, 'I had my children vaccinated

and I'd do it again!' As if that is any recommendation; when she knew I didn't blindly believe doctors anyway."

Health professionals use power (she uses the word 'we' to give her more credibility by being part of all doctors) to make their patients go along with their point of view.

The interviewees learned quite quickly how to protect themselves from intimidation and avoid confrontation by not challenging the potential perpetrator.

Karen: *"You know, this isn't even you making decisions about yourself, this is emotional blackmail, it isn't science."*

Morag, who came across as rather confused about vaccinations on some occasions, but also showed her respect for the medical profession by attending appointments, became very upset when she experienced abuse from a consultant who used his position as an authority to undermine her competence as a mother:

Morag: *"My son has a nut allergy, so we have been back and forth once a year to the clinic, and to talk to them. And on two of those visits, they kind of looked and said, 'Oh, I notice you haven't had him vaccinated!' One in particular said 'Oh, I nursed a child...if you'd seen a child with diphtheria...' a real emotional and emotional blackmail. In the end I said to him, 'Look, I'm sorry, I'm not here to talk to you about vaccinations, and you can make a separate appointment if you want to but I'm not doing that now.' It was making me feel really bad and was going nowhere with that conversation. We only got to see a consultant once a year and it was always someone different, which was bad enough without having to be diverted to some other argument."*

h. Viewing vaccinations as damaging

Martha: *"If you ask me what I think would happen if I was to take Jamie along to be vaccinated now, I can almost see his face looking at me and saying, 'What's this about?' You know, 'Why do I have to go through this?' It makes me think that the whole being of the child would make me think a mixture of horror and alarm and self protection, thinking about that. I am feeling very abused when I think about that."*

Melanie: *"I would much rather have members of the medical profession thinking I'm an utter idiot if it means I keep my son safe. I've seen what it does, all of my friends' kids, they change after they've had their first jabs."*

The perception or observation that children change after a vaccination that they lose their vitality somewhat was frequently mentioned.

Martha: *“I would be putting something in my child, some kind of burden on my child that he would have to deal with. I am protecting my child from abuse by not having him vaccinated.”*

If child abuse consists of doing something to a child which might harm them for life, or is something which may hurt them either psychologically or physically, or is doing something to that child against the child’s will; then people who regard vaccination as doing all those things, these respondents, could regard vaccination as child abuse.

Amanda: *“When I took her to get weighed at the medical centre, I heard a baby crying, it was one of those strange shrill cries and I knew it was getting vaccinated. So I asked the health visitor, ‘Is that baby getting vaccinated?’ And yes, it was. It just sounded unnatural to me. Because I study herbal medicine I learned about strange crying in class and how it can mean that the nervous system is being affected, under pressure or attacked. So to me, I made that connection, whether it is medically true or not I don’t know, I just thought, ‘No, I don’t want to hurt her nervous system.’ It just felt like that that child was being abused at the time.”*

Section 2 Un-vaccinated children; how are they different?

a. Unvaccinated children are perceived as healthier or different by the respondents.

The idea that unvaccinated children are somehow healthier than their vaccinated contemporaries was frequently mentioned. Although how this could be quantified was often problematic.

Pam: *“So she has three children and then this one who hasn’t had any vaccinations. He is ten times healthier than her other children.”*

A dramatic statement to say that the unvaccinated child is much healthier, but nevertheless mentioned as observed by all parents in the research in some degree.

Astrid: *“He’s now seeing a homeopath who said one day; “Well. You must realise that non-vaccinated children have far more energy than vaccinated children.” And it’s true, what a lovely boy, he does have a lot of energy! He is always very noisy, full of it all you know, can walk for miles and can cycle as well. I guess there is the benefit. When you read books, read magazines, hear people talking, I can see that he is a very very healthy child. You never know what would have happened if he had been immunized, what side effects there might have been.”*

Astrid feels that having plenty of energy, being “full of it all” and having plenty of stamina all illustrates excellent health. She did tell me that she can’t predict what would have happened if he had been vaccinated.

James: *“It’s hard to say if she is healthier for not being vaccinated, as I don’t know what she would be like otherwise. It is very hard to find someone to compare her with. I think she appears very healthy, she appears happy.”*

James finds it difficult to say anything out of his own conviction, perhaps as a scientist he feels he has to back every statement with a logical explanation, which is just not possible to do in this case.

Melanie: *“The play group we go to on a Tuesday which is at the same time as the vaccine clinic, in the same building. The children sort of, they have their jabs and then they come to the playgroup. It starts off with their eyes being sort of glazed over. They are not alert. Like something has shut down. You see that over time. My son had his second birthday party last week. He is so well adjusted, he will play with anybody. He doesn’t care if we are in the room or not, he is not clingy, not whiny. Yes he gets coughs and colds like other kids, they kind of go through and they finish. Whilst with a lot of toddlers, they have constant coughs and colds and streaming noses. And there is just something about the energy which is different, a level of vibrancy and energy than with the other children; it just feels like it is suppressed with them..., like a big blanket over them. I know it sounds really weird.”*

She sees the vaccination of children as a kind of drugging (“*their eyes being glazed over*”) or suppression of their personality (“*Like something shut down*”). Melanie is explaining the subtle energy level effect of vaccination on children. Something many people experience and talk about, but very difficult to talk about in science or health terms, so it often sounds somewhat woolly or new age when they do. She also admits this by saying: “I know it sounds really weird”, but it is something that I have

heard numerous people say in different ways, mothers, grandmothers and people who work with children have all told me about their experience of observing a change in children directly after vaccination. This may be regarded as “folk wisdom” by medical-sociology and anthropology (Santino 1985) it also sets up a powerful resonance in the more recent way of understanding many modern diseases as iatrogenic or drug induced.

b. Perceptions of what it means to be healthy

When asked what it meant to be healthy, the most frequent reply was ‘to have fewer illnesses’ and to have ‘more energy’ (like Astrid’s son above). There was more to it than that however. Some of the respondents expressed their views on what it meant to be healthy in quite a different way. Health was not just about a lack of diagnosable illnesses or complaints, it was also about positive energy; about a visible and noticeable clarity within the child and a strength of character and individuality which some respondents noticed in their own and other people’s unvaccinated children.

Pam: *“She does have an awful lot less of illnesses than the other kids at nursery.”*

This is a quantifiable difference that can be checked.

Jessica: *“I don’t have that much experience with other children, but with my own child, she is very lovely. Very very lively. She has always been very alert and interested in everything around her, quite sort of bouncy and boisterous. She is uhm, she has always been very strong, sort of uhm... You know newborn babies they always, gosh, hold on to their heads in the first few weeks uhm, you never had to do that with her. She lifted her head up, not quite straight away, but she was never sort of floppy and fragile looking. She’s quite sort of sturdy on her feet. Did many physical things quite early like sitting up and crawling and pulling her-self up to standing and that kind of thing. So she is very sort of physically adventurous and strong. Uhm, I don’t know, this is going to sound like ‘doting mother’ here. She’s very alert, very with it. She likes to know what is going on, like if she hears a noise around the house, she likes to go and investigate. And she has, so far been incredibly healthy. You can’t really say why, or what would have been otherwise.”*

Although Jessica has had very little experience with babies, she seemed to know everything about child development. She has taken parenting very seriously. By reading many books, asking questions and being aware and interested in health and child development she is able to make informed opinions about her child's health and wellbeing. I encouraged her to talk about her child, she was at first hesitant as she didn't want to sound as if she were boasting, but I wanted to know more about how she thought about her child's health. For Jessica also, the mental alertness, the curiosity her child displayed, indicated just as much about her health status as her ability to overcome minor illnesses.

Melanie: *"Many colds and flu that other children get she doesn't seem to get. Other children in her class do seem to be off school a lot more than she is".*

Melanie like Pam sees her child as being off school less than other children, catching fewer illnesses. She is therefore healthier than her vaccinated contemporaries in her opinion.

Martha: *"He is really incredibly healthy. The picture of blooming health and he even seems to have less of the minor things that children get, so I feel that he is stronger for it (not being vaccinated)."*

To Martha, healthier means stronger and healthier equals being more resistant to disease.

Morag: *"My sister's children for example. Her children, particularly her son, constantly have colds and coughs, nothing serious, but constantly under the weather. Neither of my children was like that at all. I just used to notice the constant snot, always down their faces. My children didn't have that."*

Many of the symptoms of health parents described that their unvaccinated children had, could of course also be ascribed to having a healthy diet and to living in a

caring, clean, supportive environment. They were very certain themselves however that not being vaccinated played a large part in the positive health of their children.

c. How they expressed that unvaccinated children are different.

Amanda: *"They are actually different looking than the average child. They've got a good strong presence and their complexions are clear, the whites of their eyes are very clear. They all have strong, it's not just strong personalities, but, they are who they are. It's like; you feel their personalities as well. I think that's something to do with not being vaccinated and having a good diet all your life. Definitely you've got to have both, and, maybe not being on antibiotics every time you are ill."*

The clarity that Amanda describes is reminiscent of Pam's wording in the previous section on the perceived drugging effect of vaccinations. There is also a suggestion that she feels that psychologically or spiritually, unvaccinated children are more themselves, have stronger identities.

Melanie: *"I think, yeh, I think that by not vaccinating Sarah, that I am letting her physically and mentally reach her full potential. And, let her be and let her have her own kind of presence. It is kind of difficult to describe, but that is what I think."*

It sounds like she feels that by not interfering in her development, she is respecting her integrity she is allowing the personal identity of the child to develop unhindered.

Astrid: *"He doesn't mind to be different, he is very much different because he eats healthy food and he does unusual things like music and playing tennis. He does his homework without being asked and he is quite proud of being like that. So far he has been respected for that because it might be ringing some bells with these young people. He might be somewhat unusual but he can stick up for himself therefore he might not be that stupid what he's doing."*

Living with being different can be used as an advantage.

Melanie thinks she can tell if children are vaccinated:

Melanie: *"I'm fairly sure I could walk into a room and tell you if a child has not had the jabs. Because it's energy is different. And you can see that. It's just something about the sparkle in the eyes."*

From the above statements it would seem that the respondents understand the vaccinations to have very deep, long-lasting negative effects on children that affect them on physical, psychological and spiritual levels.

d. Positive health-care options/what they did to keep their child well.

All the respondents actively searched for and provided what they saw as positive health-care options in; childcare, nutrition and life style. What they saw as important varied.

Helen: *"We use organic produce and we have a book, 'Food that boosts the immune system', we kind of follow that. I cook for my baby, don't use jars or baby foods."*

Something like cooking for your child, which was quite a novelty in the 1980's and 90's thanks to Heinz mostly and the shortage of good fresh vegetable in the local shops, has made a comeback. Now that cooking and growing vegetable is seen as a positive thing both for health of the individual and for the planet, cooking for babies is also possible again. I do remember meeting parents in the 70's 80's and early nineties who thought that you could only bottle feed babies and could only give them food out of jars, that there was no safe alternative.

James: *"Pretty much all the food she has had has been vegetarian and home made and we know what goes in."*

Knowing what goes in, being aware; being vegetarian is seen as different and healthier.

Jane: *"I do feel that we look after health in our family in a way that is dimensionally different. We eat food which is organic and locally produced as much as possible, in a way that my sister for example doesn't get an organic box, shops in supermarkets and to me she is getting a lot of chemicals in her body from food stuffs as well."*

Organically grown is seen as healthier. Locally produced is perceived as healthier. Added chemicals is regarded not healthy.

Pam: *“Good health is the only way to achieve anything. That is the reason why I only feed my children well. Go outside a lot, they get sunshine on their skin. They do what kids should be doing. So many kids just watch television all day. That is just rubbish. When people think it is normal, to feed a child chips and fish fingers, or chicken nuggets or burgers, because they wouldn’t eat what the rest of the family are eating, they think that that is what the kids will eat. They don’t give them water! ‘Oh no’, they say, ‘My kids would never drink water; I have to give them squash’! If you would give them water in the first place! I breast fed both of mine till they were 18 months, one was 17 months and I believe I’ve done everything I possibly can. I feed them healthily; only on very rare occasions do they get rubbish. We never have crisps in the house. If anyone asks me, ‘Oh, how do your children keep so healthy?’ I tell ehm!”*

Sunshine on the skin is healthy. Fresh air is healthy. Drinking water is healthy.

Breastfeeding is healthy. Eating with the family is healthy. Eating frozen pre-cooked and deep-fried foods is perceived as unhealthy. Drinking squash instead of water is unhealthy. Feeding children separately from the family is seen as unhealthy.

Having crisps in the house is seen as unhealthy:

Jessica: *“I want to strengthen her own immune system, which is designed to protect her. With, you know, being very careful about what she eats. Organic food wherever possible, a nice balanced diet, you know, all sorts of things that will help her be healthy, you know.”*

A balanced diet is seen as healthy:

Morag: *“I’m very careful of their diets as well, particularly because of my daughter’s eczema. Things like sleep and rest when they need it, we don’t overdo it at all. Things that I thought were important already and I was very glad that the school they are at enforces that. Holding back the tide of commercialisation, and anything else that the school does well, I kind of look at taking all those factors into account. I think they are very important, particularly sleep actually. I’m not the sort of parent...; we never go out dragging the children along. To the point that my and David’s (husband) social life suffered quite considerably over the years. They get their full 12 hours.”*

Morag was very happy to have found a school for her children where some of her own ideology about childrearing is upheld and enforced. She seemed to disapprove of the practice of “dragging children along” and named sleep, enough sleep, as being

paramount to good health. The sacrifice of their social life is seen as a necessary consequence of providing a good health framework for their children.

Melanie: *“It’s not that we are not vaccinating and doing nothing.”*

The factors they thought of as important for establishing and maintaining health were:

1. Natural childbirth
2. Breast feeding
3. Fresh air
4. Natural fabric on their skin
5. Few or no plastic toys.
6. Good balanced diet.
 - a) Vegetarian
 - b) Organic
 - c) Fresh
 - d) No junk food
 - e) No crisps/sweets
 - f) No diluting juice
 - g) No processed food
7. Preserving childhood innocence/lack of commercialisation
8. Good long sleep/rest
9. Plenty of exercise
10. No vaccinations, no medications.
11. No loud noises or bright artificial lights

These were the main things mentioned by the respondents during the interviews as important factors carried out in various permutations for the bringing up of their healthy children.

Summary

Chapter 5 dealt with many of the experiences central to the non-vaccination narrative. Their fears, and the fears they mentioned others have of them as non vaccinators was explored. How they dealt with others and how others treated them was discussed. Some of the difficulties encountered within the health service were heard also. What they think about vaccinating and the damage it might do ended

section 1 of the chapter. Then in section 2, the narrative of how they saw their children as being healthier and different and what that means and how they achieve such health, was explored.

In the next chapter, chapter 6, some of the concepts the respondents have taken to heart and which are important to them and inform their choice to be a non vaccinator are explored.

Chapter 6 Medical, Philosophical and Political Concepts

Introduction

Chapter 6 focuses on the concepts inherent in the vaccination debates; it is divided into 5 sections. The concept ‘natural immunity vs. medically acquired immunity’, how the respondents understood those ideas and the impact of that understanding on their decision-making is discussed in section 1. The positive effect of illness and the purpose of illness are discussed in section 2. Then alternative and complementary medicine is discussed in section 3, as all the respondents had been or were still either patients or practitioners of these forms of medicine. Section 4 touches on herd immunity. I would have liked to have written a lot more on herd immunity but, after researching the subject I have realised that it is a large subject on its own based largely on mathematical modelling and outside of the scope of this thesis. The last section in this chapter, section 5, touches on the interaction between the respondents with politics, the NHS, medicalisation and pharmaceuticals.

1. “Natural immunity” versus “medically acquired immunity”

The majority of the interviewees had issues with, and couldn’t agree with, the thinking underpinning the practice of medical vaccinations/immunisations. They expressed their views in various ways depending on their background and life-style. They believed that acquiring immunity, in what was called ‘a natural way’, without medical intervention, was preferable to having what several respondents called ‘the temporary and partial’ immunity provided by vaccinations. They expressed this in various ways:

Melanie: *“And I, particularly looking at vaccine theory and how vaccines work and thinking well if you catch the disease, you are immune for life, if you have a vaccine, with a lot of them, there is a 50-70% chance they will work, then they only work for a couple of years. How can that be true immunity?”*

That Melanie has spent a great deal of time and energy studying vaccinations including vaccine theory is evident from her response. The question, whether medically acquired immunity via the vaccination route is ‘true’ immunity suggests that she believes that by contracting and having the disease naturally, by catching it spontaneously from someone or somewhere is preferable because it confers lifelong protection and real or ‘true’ immunity implying perhaps that vaccines impart temporary and partial immunity or ‘false’ immunity and that, in her view, cannot realistically be termed true immunity. This highlights again, the complexity of immunity and vaccination and that the amount of knowledge needed to make an informed choice by a parent, or indeed an informed suggestion by a health professional is perhaps frequently beyond the boundaries of their knowledge.

Jessica: *“As a preventative thing, good general, overall health is much more desirable and probably more effective than medical intervention when it isn’t needed.”*

The way she saw it was that good general health confers more protection on the individual’s long-term wellbeing than medical intervention which may have unknown deleterious effects in the long term. That medically acquired partial immunity might be the cause of more unforeseen trouble was frequently brought up.

Helen: *“My friend from University, the one who wasn’t vaccinated, had a blood test for German measles when she was pregnant and she was found to test positively for German measles antibodies, where my other friend, who had been vaccinated tested negative for the antibodies. So I guessed it doesn’t actually work really, it wears off.”*

Most of the interviewees had only experienced non vaccination with one generation. I did interview several other people out with this project who had longer experience

with the practice. Two of these people mentioned the dangers of measles and mumps in young adults, who had been vaccinated as youngsters but where the vaccinations had either 'worn off' or the disease had changed to such a degree that they were no longer immune from these diseases. Reports of large numbers of cases of measles among vaccinated children caused a loss of confidence in the vaccination programme in one study. It was thought that it also lead to a lack of community motivation seeking and supporting vaccination programmes (Tayil 1998). There was also a general belief that perhaps these illnesses could pose more dangers in adults than they would in children, therefore having natural lifelong immunity from having had the illnesses in childhood would be much safer in the long run.

Karen brought up what she saw as the dichotomy ensuing from the practice of vaccinating girls of fourteen with the German measles vaccine which, if they hadn't had the German measles naturally by then, might make it more difficult for them to catch it naturally before they became pregnant in their twenties or thirties, by which time the vaccine could have worn off; thus making them more vulnerable to catching it during pregnancy, rather than protecting them when most needed. The reply she was usually given to convince her otherwise was that by having the vaccination for her daughters, they would be protecting other pregnant mothers who hadn't had the disease naturally in childhood. This was rather a difficult concept for the respondent to swallow, as she reasoned that, even if she did believe that the vaccination would work that way, there never would be a vaccination program to cover all humanity, making that reasoning, she thought, rather fallacious. Helen also felt there was a problem with the Rubella vaccine for a very different reason:

Helen: *"The ones which we sort of hesitated longer and talked about and thought about most are the ones where the illness is actually dangerous for other mothers,*

for example when you are pregnant, things like Rubella, where the immunisation is not necessarily to protect the child from the illness...

Researcher: “*MhMhMh*”

Helen: “*...it is to stop them giving it to somebody else. 'Cos we thought, well, that is quite a responsibility, you know, it is a step that is not just affecting our own family.*”

Researcher: “*MhMh.*”

Helen: “*We then decided that it is their responsibility rather than anyone else’s that it is up to them to protect their own family and we decided then not to give our children any of the vaccinations.*”

Helen highlights the difficulty in balancing personal and social responsibilities as presented to some of the interviewees by health visitors in particular. That a parent’s ultimate responsibility was to their own child rather than to society as a whole was deemed the only acceptable outcome by these respondents. They didn’t feel it was in their remit as citizens to potentially damage their own children by vaccinating them in the best interest of society at large, especially since they didn’t believe that it was actually in the best interest of society anyway.

These were some of the difficulties that were brought up as obstacles to agreeing to vaccination by the respondents and highlight the different ways that non-vaccinators think about naturally developed immunity and medically acquired immunity.

2. Positive effects of illness and the purpose of illness

That illnesses may serve a purpose was another concept which came up with some of the respondents. They believed that by allowing a child to experience a self limiting benign illness without medical intervention and by not suppressing the symptoms they were actually helping their child to become healthier.

Helen: “*Since she has been at nursery she came out with a huge fever. We took her to the GP for a diagnosis and consulted our homeopath but she got through it*”

without medical help. After she recovered she was so remarkably much healthier, glowing with health. She is just so strong after that. I describe it as a storm that blew away all the things she had attracted from nursery."

A metaphor for cleansing and purifying the child perhaps. This implies much about her philosophy of health and illness. Such as: health is clean, illness is dirty and health is innate, illness is conferred by others or by the environment.

Karen: *"Well I see the childhood illnesses as having a purpose. I do appreciate that I live in a society where many of them, like polio, aren't a threat like they used to be, so I do have, I am lucky to be able to make that decision. Where something like chickenpox or measles or any of the others I feel it is beneficial for the children to experience it. Yes, there are risks with not having the vaccinations, but equally, there, it goes both ways. I would prefer to have that possibility of change for the child rather than prevent it."*

Researcher: "Can you say a bit more about why you would want them to have those illnesses?"

Karen: *"Because my understanding of them is that it is an opportunity for them to overcome certain hereditary or other, let's see, how do I put this; it's to let go of certain hereditary traits and then move into their own. When you see a change in your child after having gone through one of these illnesses it's like they've broken through something by, you know, after the illness. I did feel as if they did move to a different stage. This is a new level in their development."*

This observation, that a child somehow changed for the better, achieved a new level of health after a childhood illness, or as Karen put it: *"to let go of certain hereditary traits and then move into their own"*, or as Helen said: *"she was so remarkably much healthier, glowing with health"*, is a concept not conventionally used in terms of recovery from illness. It is not a concept inherent within homeopathic philosophy per se either. It is mentioned in anthroposophical medical literature (Goebel 1988) but since neither Helen, nor James (see next quotation) had mentioned anthroposophical medicine or ideology at all, nor had any relationship with Waldorf Rudolf Steiner Schools as far as I was aware, I surmise that this is purely their own observation and not influenced by the philosophy of others (I did look out for clues

of connections to such organisations). Karen has a relationship with anthroposophical medicine and she did tell me that she has this understanding from what she has learned from Anthroposophical medical and pedagogical (she is a Waldorf school teacher) philosophy (Wolf 1982). That is not to say that she has not also noticed a positive effect on a child's development after an illness herself. Her observation is expressed more in developmental terms than only in terms of just physical health. She says: "*has broken through something*", like a barrier or an obstacle. Karen also talks about "*the purpose*" of illness. That illness might have a purpose and therefore a meaning, is something which is not generally thought of and would change fundamentally one's way of handling or indeed wanting to prevent, such an event as a childhood illness. Her quotation also conveys a particular understanding about hereditary traits as something you can get over.

James: "*She has been affected by the normal nursery illnesses and she fought them off quite comfortably, some of them knocked her out for a wee while but she bounced back even stronger afterward. We've seen major positive changes in her afterwards. We feel she is very strong and I think we have made the right decision.*"

James, who refers to himself as a scientist who wants evidence (see his other quotes in previous chapters), said he noticed a positive change in his daughter's health after an acute childhood illness. It is interesting that he does often say 'we' instead of 'I', inferring perhaps that his partner and himself are of the same opinion, or perhaps because he doesn't feel confident he himself observed the change, or isn't confident that it is 'scientific' to make such a statement but that he and his partner share this belief.

Amanda: "*So people who can't bear their children being ill so they would actually rather they never got ill, but they don't realise that being ill is part of being strong, like immunity wise.*"

Amanda's view point on the parents' wish to prevent their children from being ill brings up many other issues regarding childhood illnesses that the respondents talked about. Some of these were:

- The issue of having to take time off work to nurse an ill child.
- The lack of nursing skills and the lack of confidence in their capabilities of looking after an ill child within our medicalised society.
- The underlying worrying idea that having an ill child somehow makes one into a 'bad' parent and the perception that a 'good' parent's children do not get ill.
- That illness is part of being well, by somehow exercising and developing the immune system was a concept held by all the respondents, which is perhaps not a view held by many members of the general public or health care professionals.

3. Alternative medicine as complementary or as primary healthcare.

All of the respondents had used alternative health professionals for advice or treatment either for themselves or their children at some point. Some went to see a practitioner as their first port of call, where others used them when the bio-medical option wasn't desirable to them, or nothing else was available to them.

Astrid: "Like I mean, since then we have all been ok and haven't been to a doctor. I go to the homeopath if something doesn't clear up by itself. My homeopath will also advise me over the phone. I don't panic a lot but I do like to talk to my homeopath. Like something like earache, I mean my oldest son had earache badly and it clears up very quickly with homeopathy."

When I asked if she also went to her GP when something like that happened, she said she didn't anymore. She did initially with her first child, but since the only thing that was ever done to help her child with earaches or coughs and other infections was to be given a prescription of antibiotics, which she didn't want to give him anyway, there really wasn't any point in going, she said.

Morag: *"I do feel quite comfortable that I could go and get advice from a homeopath if I was seriously worried about something."*

In some ways, Homeopaths seem to have taken over the role of family doctor for many of these interviewees. They might get a diagnosis from a GP, or an opinion, but they generally were not happy with the treatment or the system or the medication and preferred to discuss things with their homeopaths and to take the alternative medicines to the drugs.

Melanie: *"She sees him every month and in fact with number two, as I'm five months pregnant, it's going to be even better because she knows it before it is even born."*

Researcher: *"You see your homeopath every month?"*

Melanie: *"Yes."*

Researcher: *"The whole family?"*

Melanie: *"All three of us actually. My husband sees her for various stuff and then Sean and I see her together every month. And it is really hard work, because I've got a history of asthma, which comes from my Dad's side of the family and I'm determined that Sean is going to grow up with healthy lungs. When I look back at the amount of antibiotics I had when I was two, because I had a urinary infection, I had my adenoids out and all sorts and I'm convinced that that kind of thing helps the asthma to flare up. Its classic you know, my breathing was fine and once all that was over basically I had severe asthma. So I have been working with my homeopath on that, you know, and at the moment as I say, my aim is for Sean to grow up being able to breathe. I know that if I went to the doctor every month instead, Sean would already be on the at risk register for asthma and eczema and allergies, he had toxic reactions to some chemicals in food. If you feed him, as at playgroup, if he accidentally gets his hands on orange juice that's got aspartame in, the next day his skin is on fire. Literally the patches the size of the palm of your hand it looks like. I would not want him to go the conventional route. And obviously I'm spending a lot of time working with my homeopath on undoing all the vaccinations I've had."*

She clearly spends quite some time and money consulting her homeopath, but this was not unusual. Melanie expresses very clearly how, in her mind, the conventional medical way of treating illness made her worse by making an acute illness into a chronic disease. That she is now working to try to reverse this damage to herself and prevent it happening to her son by using homeopathy, shows great faith and self reliance. From my conversations with homeopaths, their perception of the damage done by vaccinations and the practice of repairing this damage with homeopathy is a well known procedure.

4. Herd immunity

The concept of herd immunity was frequently mentioned, both as a scientific hypothesis and as a social phenomenon. However, all the respondents had issues with the idea of herd immunity. The concept 'herd immunity' itself was problematic to the respondents, but also the way the concept was sometimes used to persuade the parents to vaccinate their children against what they felt was their own better judgment.

Hugh: *"There is a sort of, I think they call it a herd immunity, when they sort of get a critical mass to do it, uhm I sense that if you said that you are not going to do it I sense that you are sort of going against the herd."*

And another reply,

Jessica: *"Sort of trying to make you feel guilty if you didn't do it. By saying it only works if 95% of the population is vaccinated, as if you are kind of letting everyone else down I felt I was being bullied by being made to feel guilty for other people's health which is not my problem."*

Jessica's quote above is a part of a much longer rather convoluted passage from the interview which indicated the difficulties she went through, agonizing over her decision and finally coming to her conclusion that she is responsible for and to her

own child first of all. That this is also the accepted attitude of the WHO is evident from the following quote from an article based on a research project on vaccinations in Russia:

“The goal of vaccination is the generation of protection of the host” (Atrasheuskaya et al.).

Not the protection of society as a whole.

Morag: *“ I found the stuff about herd immunity, I really felt was a, not covert, it isn’t quite that sinister, it was a way of trying to put some kind of social or moral responsibility on people that I believe is not there.”*

Morag, as a scientist, did not believe in the science of herd immunity.

On people who vaccinate even though they don’t believe in it and herd immunity:

Pam: *“I think they feel guilty, but they can’t face the thought of not doing it, in case something happened. They do what the majority do. They have a herd mentality. Like lambs to the slaughter. They think, ‘Well, he does it and everyone else does it so I can’t go against that’, so. I don’t know...we talk about herd immunity! (Joint laughter, inferring herd mentality?)*

Researcher: *“What do you think about that, herd immunity?”*

Pam: *“A load of rubbish. I read somewhere that the term ‘herd immunity’ came originally from the natural herd immunity that we get. I was sure that 30% of the herd had to have had the disease for the rest of the herd to be ah covered.”*

Researcher: *Mhmmh* (indicating that I’m listening)

Pam: *“With the natural disease. Where now they are talking like something in the region of 90% with vaccination. It’s rubbish. It’s no good believing what the doctors say when they are getting paid to do it, its no different than taking advice from a butcher about becoming a vegetarian”.*

Researcher: *“(Laughter) that’s a nice analogy, yeah.”*

Pam: *“You listen to what they’ve got to say and at the same time, I don’t trust them at all.”*

Pam clearly understands the idea of natural herd immunity but does not believe that vaccinations impart the same kind of protection as natural immunity or that the

numbers, used by vaccination promoters have any bearing on reality and are only used to support the vaccination theory and the vaccination program.

Morag: "Then when I started looking at what the rationale for vaccination, uhm herd immunity thing and stuff and things like that, it didn't really make sense to me. The questions I had about what research had been done on the long term effects on the immune system and that kind of thing, I never had an answer to that because I don't think there is one, probably nobody knows. I was concerned about that. The idea that you have to have a certain, a certain percentage of people vaccinated against a disease, that will then protect everybody, I don't believe it. I don't think you can put a percentage on it. It sounds to me too much to me like a public health, a political way of persuading people. That if they don't do it, they are putting other people at risk. The way that the vaccination program is administered anyway it is much more to do with administration rather than it is about protecting people's health."

The concept of herd immunity as it is used in the vaccination debate, was not accepted by the respondents as being either a scientifically correct or a socially acceptable ideology for promoting community or individual health.

To find out more about what is meant by the term "herd immunity" I have done quite some reading on the subject and although it is very interesting, it is very theoretical and mathematical and perhaps not of particularly of value to individual parents (Anderson 1991; van den Hof *et al.* 2002). Some of the more radical respondents in this research did feel that it was used as a weapon, as does Dew:

"The technology of immunisation can be seen as another powerful tool in subsuming the individual to the collective will, where the concept of herd immunity is invoked to foster coercive campaigns to increase compliance with technology" (Dew 1999).

5. Politics, Medicalisation, Pharmaceuticals, the government and the NHS

That politics played a large part in the peoples choices and varications and indeed in the practice of vaccination generally is undeniable. The so called 'medicalisation' of the population was touched upon by several respondents as a reason for the lack of confidence in home health care and in parent's loss of confidence in their ability to

deal with everyday illnesses. Even birth and death, once the domain of family and community women, have been taken over by “professionals”, and pain, physical and mental, are no longer to be part of life’s experiences without medical intervention by a state authorized professional (Illich 1977). Politics and medicine have become inexorably intertwined.

Hugh: “Well, you get on a kind of train in the beginning of life in the hospital and you sort of kept on that and you kind of depend on your relationship with the state, and the products from the drug companies, your relationship with the health services, social services whatever, it causes a kind of dependency. But somehow it has gotten out of hand.”

Morag: “Another thing the health service has done, they have deskilled ordinary people from being able to nurse particularly children.”

Melanie: “Medicalisation has grown so fast that things like good food and common sense have really been sidelined and are not being taken into account.”

This ‘medicalisation’ of the population depends on or is fostered by the inter-relationships of the pharmaceutical industry, the government health department and the professionals who provide health care. It then infiltrates the public consciousness through the media, educational institutions and other means.

Morag: “When the media coverage about the MMR stuff happened, in fact I thought that the Government spokes-persons have been doing themselves a disservice. The way they had been speaking has contributed to putting people off, has added to people being put off, because they were so patronising and so very dogmatic really about it and not taking into account any possibility that the parents might want to choose or do things differently. I suppose they are stuck with this rigid idea that, of herd immunity that you have to have that many people done and in order to get them you’ve got to get them thru the door and get them out again. The pharmaceutical companies are always on the lookout for the next big money earners aren’t they, which adds a skew to the whole thing.”

Those respondents who were aware of the relationships between the pharmaceutical industry and the government health policies and the politics of health, were very cynical about the recommendations made by their state supported health care providers and didn’t feel able to trust them to be non-biased.

Melanie: “ When you’ve got the drug companies effectively, running the country over here, telling the government how many doses of Tamiflu they need only just before we find out that the strain of bird flu is actually resistant to it, and we have 14 million useless doses. You know, the government is not going to back track. They keep very quiet about it. They have spent all our money on drugs that were miss-sold. The government still says Aspartame is safe, even though there is so much evidence that it is not. While the drug companies are running the country, then we are not going to have the medical profession being brave enough to stand up and say actually, there is a problem.”

Many of the respondents said that they didn’t feel able to trust the government policies on vaccination because of the government’s relationships with drug companies, and the drug companies’ ulterior financial motives.

Researcher: *“Why is the government promoting vaccinations?”*

Pam: *“Because of the ...the corrupt Pharmaceutical industry and other big corporations. It’s all the same, the Guns industry, Pharmaceutical, everything.”*

Researcher: *“Yeh?”*

Pam: *“These industries are giving the government big money. They are the ones running the country really. And the doctors are being taught everything they know from the pharmaceutical net, they are hardly getting an unbiased line from them.”*

These above two respondents, who were politically aware, also made a political statement by not vaccinating their children. It was not just the vaccination policies which were being questioned; sometimes the whole ‘drug culture’ was in question.

Karen: *“I have a big question about the health service. They won’t even look at the child, regardless of what age they are, unless you buy into the drug culture.”*

This last comment was in relation to the an incident with NHS 24 where the client asked for a doctor to come out on out of hours emergency call and was told that she should give the child paracetamol and call back in 24 hours, which wasn’t acceptable to the client and she did not do that kind of thing (give paracetamol to a child) and would never call out an emergency doctor unless she felt it absolutely necessary.

The pressure that medical professionals are put under by the government health policies and the financial incentives put in place by them to ensure that as many children as possible are vaccinated was sometimes seen as corruption but also as a disadvantage for GP's, as it made life difficult for them and undermined their freedom to practice wisely and to personalise their practicing. As expressed by this respondent;

James: *"Their credibility (GP's) is undermined by the government in part as well. So it is very hard to get impartial advice from your GP on this matter because of the strong financial incentive. There you're undermining their credibility."*

The political positioning of the respondents, varied greatly. From being sympathetic to the difficult role GPs now play, like James above in having to balance government incentives, morality and responsibility, to downright fury, indignation and bitterness at what was perceived as the corruption of the pharmaceutical industry and the lack of power or weakness of the medical profession and the government to stand up to this '*huge evil dragon*' as one respondent called it.

Summary

From natural immunity to medically acquired immunity, from the purpose of illness, alternative medicine and herd immunity; this chapter explored some of the larger themes in the vaccination debate as perceived by the respondents in this project. Herd immunity; such a problem for the interviewees, medicalisation, the government's involvement in health care and the role of pharmaceuticals, all these were potent issues the respondents had something to say about. They are also all issues which help to uncover the health beliefs of the modern world of bio medical care provision.

In the final chapter, chapter 7, the thesis will come together in a summary of the whole project and say something about what can be learned from this research and about possible future research that might be done to develop this work further.

Chapter 7. Discussion/Conclusion

Introduction

This thesis examined the views and experiences of people who had decided not to vaccinate their children or themselves, including those who had previously vaccinated and those who said they might vaccinate again in the future. A sample of 15 people was interviewed using a constructivist and a feminist approach. These in-depth interviews were analysed using post modern qualitative research techniques which focussed on narratives. The aim was to explore these respondents' health beliefs and experiences in the context of their lives and families, including how they dealt with health care providers, other parents and school on a day to day basis. Because to vaccinate is the norm and since vaccination is promoted and advised by the health care system this group of people can be thought of as going against the mainstream. Their accounts did indeed reveal aspects of their felt stigma and blame. The primary purpose of this research was to explore health and vaccination from the point of view of these respondents. Since most research has focussed on parents who do vaccinate or has treated non vaccination as a challenge to be overcome by the health service, the exploration of health beliefs and practices of people who do not believe that vaccination is necessarily in the best interest of their children, attempts to understand this different viewpoint. This may help to remove barriers to communication and understanding and can facilitate bridge building between the health service and the unvaccinated community. Although vaccination is not without controversy or public debate in the UK, most people do participate in vaccination programmes. Thus this sample can be considered unusual as the majority of the public will still have the vaccinations, even when they are not sure about them and

may feel some anxiety (Evans *et al.* 2001; Hilton *et al.* 2006; Rogers and Pilgrim 1995; Skea *et al.* 2008). Though it is difficult to say how different the respondents in my study are, in terms of their health beliefs and experiences, they do differ from most of the population in that they decided not to vaccinate their children in most situations.

This final discussion/conclusion chapter is organised in four sections. First in Section 1, a short overview of the whole thesis is provided, split up into four parts (a, b, c and d), reflecting the broad divisions of the thesis. In part a), a history of vaccination is the main focus. Then in b), sociological, anthropological and philosophical aspects of vaccination are looked at and the concept of risk in relation to vaccination is briefly discussed. In part c), the methods used in the research and the strengths and weaknesses of the project are explored. And finally in part d), of section 1, the analyses chapters of the thesis, 4, 5, and 6 are summarised as a prelude to the broader discussion that comprises section 2 of this chapter.

In section 2, a number of the themes that emerged during the analyses of the narratives are brought out and further explored with the intention of drawing out indications of health beliefs and practices that underpin the respondents' choices in healthcare and healthcare interventions. It is divided into five sub-sections or parts. Part a) starts with a consideration of vaccinations as an element of our everyday healthcare programmes, the system as it is practised today. Part b) discusses the evidence of resistance to and concern about the vaccination programmes and the possible relationship between a non-vaccination stance and alternative medicine. This indicates the non vaccinators' active engagement with taking care of their families' health and also their rejection, in some cases, of bio medical practices and

values. Then in part c) the role of public health within society is critically discussed. The respondents' experience of public health's lack of support for diversity and different health beliefs is highlighted. Part d) explores the views and experiences of non-vaccinating parents and compares these to those of vaccinating parents as gleaned from others' research. Part e) discusses the impact of the quantity of vaccinations now available and promoted for all children in the UK.

Section 3 explores what this research project has added to the knowledge of and decision making about parental understanding of vaccination and health beliefs by placing it into the context of others' research in the field of the sociology of vaccination. Issues of responsibility, informed consent and choice in health care interventions are also explored. This research attempts to show why and how some parents with anxieties and misgivings about bio medical interventions think and act when they make an informed choice not to vaccinate. It also demonstrates the ontology of certain health beliefs that don't fit in with bio medical interventions. In the final section of this conclusion chapter, in Section 4 suggestions are made for possible future action and research.

Section 1. Summary of thesis

a. Background research: The history of medicine, science and public health provision and vaccination

In order to provide some context for understanding the respondents in my research better, the epistemology of vaccination within the UK, and how it came to become such an important arm in public health, must be taken into account. To begin to understand how vaccinations became the norm in western post modern society it

seemed important to place the practice in its historical setting, and then consider how the interviewees in my study responded to this norm.

The first historical accounts of the practice of vaccination and/or inoculation in the western world by a medical doctor came from the works of Edward Jenner in 1798. He changed what may previously have been a folk tradition (Bazin 2001) into a medical procedure. However, it took many years to make vaccinations acceptable to medicine. The 19th and 20th centuries progressed and science caught up with the actual practice of vaccination by the discovery of microbes, bacteria and then viruses. Medical doctors, previously all empiricists, now also embraced science (Ackerknecht 1982). The need for scientific evidence, though crucial now, was preceded by the need for experience, faith and community support. Shortly before the scientification of medicine, vigorous public health measures were put in place. Tremendous feats of civil engineering such as the sewerage system, the provision of water, the rubbish collection programs and rat and vermin extermination programs were accomplished, particularly in Western Europe and the UK. All these measures made a huge difference to the severity and frequency of epidemics and to the experience of health and well being of the population as a whole (Rosen 1958; Lambert 1963). Although health was improving in the 1850s and the incidence of small pox trailed far behind deaths from measles, scarlet fever, whooping cough, dysentery, diphtheria and cholera, the Compulsory Vaccination Act (smallpox) was passed by parliament in 1853 (Durbach 2005). There was huge public dissent to this Act and in 1906, 174 MPs were voted into parliament on this one issue alone and the Act was repealed. Controversies have been part of the development of vaccinations ever since. The polio vaccines were controversial in the middle of the 20th century;

the whooping cough and the rubella vaccines also caused great debate, litigation, non compliance and controversy when they were launched.

More recently the MMR (1990's) and HPV (2008) vaccines and now the swine flu vaccine (2009) also have their sceptics, critics and abstainers, both professional and lay. Since 1906 it has been an issue of individual conscience/choice whether people in the UK vaccinate their children or not (Colgrove 2006). And, most people do vaccinate. However, for some diseases vaccination has a much lower uptake than others, even when they are easily available, for example for seasonal flu (Harrington *et al.* 2000; Fitzgerald *et al.* 2006)

b. The sociology, anthropology and philosophy of health and illness in relation to vaccination

In Chapter 2, the thesis examined the sociology and the anthropology of health and illness in relation to vaccinations. The biomedical model of health and the concept of dualism within the philosophy of medicine and how this world view affects and underpins our present public health policy and our understanding of health and disease are discussed. The ontology of duty, prevention and power within the medical frame, and the idea of the sociology “of” medicine and the sociology “in” medicine as first written about by Robert Straus (Straus 1957) are explored. The concept of risk as it is used in sociology is discussed in some depth in the chapter in section 3. Risk, so important in the making of decisions in public health, loses its poignancy and significance somewhat when the subject of the risk analysis exercise has a different purpose in mind. Public health's remit is to lower the death/disease rate in a large group of people; the individual parent wants to protect his or her own

child from harm. These are very different aims and pose fundamental challenges to public health and to parents making vaccination decisions.

Then the chapter goes on to discuss others' research. Several diverse studies both British and American are discussed and the outcomes, differences and similarities are compared to the research undertaken for this thesis. The research published in 1991 by Suzanne New called "I don't believe in needles" comprised of analysis from the qualitative data of a largely quantitative case-controlled study on uptake of infant immunisation in two district health authorities in the North West of England. This research shed new light on the sociology of vaccination by revealing the effects on uptake and public perception due to vaccine damage and vaccine failure and the influence of the press on uptake (this was the pertussis "scandal" of 1974-1986). This was also one of the first peer reviewed published studies that showed that there was another category of parent: besides the complete and incomplete vaccinators, there was also a small minority of abstainers. Other studies are discussed in the chapter also, including the more recent study undertaken by Hilton et al in 2003, which found that the MMR debate continued to raise important and wide ranging issues in relation to perceived conflicts of interest, and lack of trust in providers of health information. For example, it was seen as a conflict of interest that GPs get paid for vaccinating children and at the same time advise them to be vaccinated. It was focus group research with:

"lessons for health professionals and governments about trust, credibility and risk which might be applicable to as yet unknown health crises and controversies" (Hilton et al. 2007).

Another study undertaken in Scotland by Skea et al, analysed scripts from an online chat-room. It developed some new conclusions about the importance of the

beliefs of the individual. Amongst the interviewees there was evidence of concern about and experience of vaccine damage with the MMR vaccine. The researchers suggested that more emphasis should be placed on herd immunity and social responsibility with future parents, but also that vaccinators should take the health status of individual children and their susceptibility to any potential harm from vaccination into account, so as to prevent vaccine damage (Skea *et al.* 2008). Since the MMR debate, the majority of articles on the subject are framed around the loss in confidence in the government health policy of mass vaccination engendered by the MMR. According to a paper published recently by Hilton *et al.*, 860 relevant articles have been published in clinical journals about the affect on uptake since the Wakefield paper was published in 1998 (Hilton *et al.* 2009). Another MMR research project, published in 2001, undertaken by Maggie Evans and Helen Stoddart from Bristol University with focus groups, in collaboration with several primary care practitioners and researchers, brought out many of the reasons and underlying anxieties held by all parents involved, both vaccinators and MMR non vaccinators (Evans *et al.* 2001). The purpose of the research was to develop understanding of the reasons for the decline in MMR uptake despite reassurances of its safety; and the need to understand what influences parents to accept or decline MMR vaccination for their children.

Fewer studies have been undertaken with the intention of exploring parents' views on vaccination out with particular health scare scenarios. One study undertaken by Gullion in Texas (Gullion, 2008), focused on understanding vaccination beliefs in women who decided not to have vaccinations for their children at all. The results of this study are not unlike my own, and emphasise the importance of acknowledging

the diversity of peoples' health beliefs and the extremely pro vaccination stance frequently encountered by patients/parents in the health service environment. It also shows that the non vaccination response is not confined to the UK.

The reviewing of this wider literature was important as it enabled similarities and differences between participants in my study and those in other research studies to be identified.

The concept of informed consent as it relates to vaccination in particular and some of the difficulties encountered in implementing this protocol within a primary care environment are also explored in this chapter. Unless health care practitioners have an active dialogue with parents and explain the possible side effects of vaccinations, informed consent cannot be said to have been obtained. Finally the sociology of women and their role as carers is explored within the feminist/health sociology literature.

c Methods, theories and obstacles, strengths and weaknesses.

Chapter 3 described in some depth how I went about achieving this project. It describes the background studies undertaken, and how the research and the writing up was carried out and accomplished. The problems and difficulties encountered during the process of the research itself are also discussed; problems such as a crisis of confidence, a difficulty with a sociological orientation, and a struggle with the ethics of undertaking such a research project at all. The change in orientation that was necessary in order to be able to undertake reflexive research after being a health practitioner for 25 years was a bigger leap than I had first imagined. The sociological methods literature was a minefield to begin with. The number of different views on qualitative research and the sheer volume of literature on the

subject take up very many shelves in the library and pages in journals. Subsequently the interviews with the respondents were undertaken, recorded and analysed using grounded theory models and practices as first put forward by Strauss and Glaser (Glaser and Strauss 1992) but with a post modern constructionist approach to bring the work up to date. Subsequently work by Kathy Charmaz (Charmaz 2007) and the practical suggestions from Rosaline Barbour (Barbour 2006), Guro Huby and Sarah Cunningham Burley, were very helpful for bringing clarity and rigour into my understanding of methods.

A narrative approach was used as this was seen as the best way to get new information and to get to the respondents' real experiences. I asked them to tell me about their experiences with vaccination. I did not have a fixed set of questions as I wanted to discover what was important to them, how they thought about the subject of vaccination, with their own children in mind. Not only what they said was listened to and recorded but also how they said it and also what they didn't or couldn't say was sometimes also noticed.

The study used purposive sampling using opportunistically selected sites to recruit from. This factor, combined with the relatively small sample may limit the transferability of the findings. Nevertheless the choice of interviewees was deliberately varied; in age, sex, number of children, whether they had used vaccinations before or never vaccinated at all and ranged from different areas of the UK. This was done to create both breadth and depth in respect of developing an understanding of non vaccinators' health beliefs and practices. My main aim was to reveal the stories of these parents, which they found were often disregarded and sometimes even classed as dangerous, to be heard. What the respondents gave me

were words, was language, was a moveable, living feast which, once analysed, becomes part of a body of belief and is not fact per se. This is the nature of qualitative research. Norman Denzin (Denzin 2003) mentions his wariness of textual strategies such as verbatim transcriptions which:

“allow readers and listeners to assimilate the performance as a realist text” (p. 40).

Notwithstanding all the obstacles hindering clarity, truth and understanding, this kind of qualitative research comes closer to finding a way of giving voice to the researched and indeed recording the ontology of people’s beliefs and practices, even though the voice of the researcher is also heard.

d. Parents’ words and parents’ views

The subsequent three chapters (4, 5 and 6) are where the analysed data from the interviews are organised, displayed and discussed. The analyses chapters are woven from the respondents’ own stories.

Chapter 4 describes how the respondents talked about the decision making process itself and is laid out into three sections. It starts in section 1 with what they expressed as their own self determination; they believed that they had made up their own minds. They saw refusing vaccinations as the only correct decision in the circumstances they found themselves in, a decision based on what they sometimes called “common sense”. Their concepts of immunity and of the immune system and their knowledge of how it works and their thoughts about how it protects the body from illness prevented them from having their children vaccinated. The ones who had no vaccinations at all felt that vaccination would actually harm their child’s immune system. The parents who had had vaccinations before felt that they no longer wanted them in the light of what they had learned about the vaccines

themselves and their beliefs about the workings of the immune system. Most of the parents interviewed mentioned ‘wholeness’ and ‘intuition’ as being important concepts in health and health protection. Intuition was mentioned as if it was an organ of perception or an internal sensor to alert them to what was safe and what was not safe to do with their child.

In section 2 of chapter 4 the influences on their decision making process are explored. They talked about being influenced by a GP or homeopath or other health professional. They mentioned the books and leaflets that had played a part in their decision making process. The few respondents who mentioned the internet used it for getting information and for networking but not for helping them decide on such difficult issues as whether to vaccinate or not. Family and friends played a large role for some interviewees, but none at all for others in influencing their decisions.

Section 3 of chapter 4 explores the health beliefs and concepts underlying their decision making. The phrase “less is more” came up a number of times in different narratives; in the context that the least amount of interference was seen as having the greatest influence on positive health outcomes. A number of different influences on beliefs were identified, from rejection of scientific evidence through to experience amongst family and friends of the limits of a vaccine’s efficacy. Nonetheless, a few respondents did believe in the efficacy of vaccinations but felt it wasn’t necessary for their child.

Lastly, respondents’ views and practices regarding vaccination also seemed to be related to a wider world view that rejected chemical intervention and supported movements such as those promoting organic and whole food, clean water and air and practices such as home birthing, outdoor activities and home schooling; suggesting

then that choosing not to vaccinate is best understood as part of a wider set of values and behaviours.

Chapter 5 focused on how respondents talked about the emotional and the social aspects of forgoing vaccinations. In the first section the struggle that many of the parents said that they had undergone within their own minds is analysed. This demonstrated that the respondents were not making their decisions lightly: with the fear of disease on the one hand and the fear of the vaccination on the other, fear and anxiety were, for some, a constant companion. Others seemed much less affected by fear and anxiety and were more confident with their choice.

Family was for some a constant area of conflict about the subject of vaccination, where for others, family was experienced as very supportive. There was one situation where the mother's family was seen as being supportive and the father's family had accused the respondent of endangering the child's life and of being a bad parent. Parents mentioned some very unhappy events, where they were ostracised, and accused of being disease carriers with their unvaccinated children and of being subversive by undermining the health of the nation as well as being ignorant. The language they used was strong, suggesting intense emotions. Due to the reported social difficulties of discussing vaccinations with close acquaintances, colleagues, family and indeed health care professionals, many said that they tended to keep quiet about the subject as the best day to day option. Feeling different, feeling outside the accepted mainstream, was for some of the respondents a painful reality. The anxiety and fear mentioned by first time parents dissipated as their children grew up and no actual serious event occurred from not being vaccinated. Indeed, as the last section of the chapter showed, the respondents reported that their

unvaccinated children seemed, to them, to be healthier, more energetic, livelier, happier and more independently intelligent than their vaccinated peers. 'Being healthy' for the respondents encompassed the body, emotions, mind and spirit; and non-vaccination was just one way of promoting good health from their point of view.

In chapter 6 some of the more prominent medical and political concepts and orientations underlying the respondents' vaccination decision are explored.

The concept of naturally acquired immunity, acquired by developing immunity from having been infected with the disease or by direct contact, or in other ways such as breastfeeding, was seen to be far superior, longer lasting and more rigorous than immunity endowed by vaccinating. Vaccinations were believed to bestow partial temporary immunity only and people said they were worried that once this 'false' immunity wore off, their children would be even more vulnerable because their immune system would have been damaged. There was also a belief that by developing immunity naturally, without vaccinations, the child's immune system would be strengthened and more able to respond to other attacks with different microbes and diseases. They believed that vaccinations weakened the immune system in the short and in the long run. Several parents mentioned that they noticed a positive health improvement, a boost in confidence and maturity, a growth spurt and an increase in wellbeing after their child had overcome a childhood illness. These beliefs and observations were also drawn out by Polterak (2005) and Evans et al (2001) in their research, showing that these concepts are not that unusual.

All the parents in the study were confident users of one or other CAM therapy. Some used homeopaths or herbalists as their primary care giver, using the GP only as a last resort or for a diagnosis. They were also on the whole conversant

with using homeopathic or herbal OTC remedies and ‘kitchen pharmacy’ or folk remedies, such as herbal teas, poultices, compresses and honey and lemon for a cough, for day to day health care support. They expressed their confidence and a sense of empowerment in being able to care for their children in this way.

The concept of herd immunity as put forward to the respondents by health professionals and by the NHS and government literature did not persuade them to take part in vaccination programmes. There was some reported experience of social coercion, that “you’d better vaccinate or you will let other people down”, which some found distasteful and unnecessary. Those parents with a more scientific background said that they didn’t agree with the science as it was explained to them. Others felt that the argument was not relevant to them; their responsibility was first and foremost to their own child and not to society as a whole. They felt that they would help society most by helping to bring up a healthy child. They couldn’t understand how damaging their own child, which they believed vaccinating would do, would in anyway help society as a whole.

The chapter ends with a small section on the perceived politics of health. The respondents regretted the apparent increased medicalisation of society and people’s declining ability to look after themselves. Several bemoaned the interference of governmental health departments with GP practice which they thought negatively affected the GP/ patient relationship and most respondents were very concerned about the possible corrupting influence of the pharmaceutical industry in the health care world as a whole.

Some of the emerging themes from the research are further explored in section 2 below.

Section 2. Vaccination today

a. Mass childhood vaccination – how did we get here

Vaccination is widely regarded as one of the most important tools in the public health arena's medicine chest. However, the mass vaccination of all children is quite a recent occurrence. To understand how vaccinations have become such an important part of present medical work there was a need to look into what changed in medicine and in society and when did these changes come about that led to the proliferation of and widespread belief in and acceptance of vaccinations. The promotion of mass childhood vaccination developed over the past 50 years, with the majority of the vaccinations being developed, marketed and made available within the past 30 years. The mass smallpox inoculation programme had its roots 150 years ago and was discontinued in the UK in the 1940's. The polio vaccination programme began in the 1950's and is still part of every child's vaccination programme today. Since the 1950s vaccinations have proliferated exponentially. It is normal in Britain, in 2008, for children to receive at least 36 vaccines in the first 18 years of their life (excluding travel vaccines) (NHS, 2008). It is quite remarkable how quickly a programme such as this can be set up and become the norm in the modern world¹. Pushed by market forces and political agendas and heavily marketed, vaccinations are promoted as a panacea for many ills (Lippman 2008). By contrast, the respondents in my research project regarded vaccinations as a health intervention and they generally didn't agree with health interventions if their child wasn't ill. They found that they could not agree with a public health system that promoted so many vaccinations and questioned whether they were either therapeutic or necessary. The paper by Evans et al, discussing the research with focus groups of

¹From approval for Merck's Gardasil in July 2006 in Canada to roll out in the UK in September 2008.

parents, explored the reasons and beliefs of parents both vaccinated and unvaccinated children and brought up some similar issues. It showed that both vaccinating and non vaccinating parents felt that the decision about MMR was difficult and stressful and a number of people had said that they had experienced unwelcome pressure from health professionals to comply (Evans *et al.* 2001). With the focus group participants, as was the case with my respondents, a key concern was the health of their own children. This was not because they relied on a herd immunity afforded by the vaccinated children in their community to protect them from illness, as suggested by some professionals. Some of the participants, like my own interviewees, did not necessarily want to prevent measles, mumps or rubella as they felt that the immunity afforded their children by naturally contracting these illnesses would be beneficial to the child's lifelong health and development generally. Like my respondents, the Evans study participants also voiced their suspicions about the GP vaccine payment schemes, about stigma and exclusion by the health service for having another viewpoint and about the lack of freedom of choice in NHS medicine. This demonstrates that the uncertainty created by the mass childhood vaccination practices is not confined to non vaccinators alone. Many parents are unhappy and suffer anxiety and stress around the practice. What was different with my respondents was that they reacted to this anxiety by and large by refusing the vaccination.

b. Resistance and objections

The respondents in my study had their own health beliefs and philosophy of health and they questioned the practice of mass vaccination. They saw it as being

wrong, dangerous and damaging to both the individual and society, as previously explained. The way the practice of mass childhood vaccination is promoted and carried out was also found to be problematic by them, because it did not allow for alternative views and approaches to maintaining children's health. Most of these respondents did not entirely reject bio-medicine, but interestingly all had some ongoing relationship with alternative/ complementary healthcare practitioners to whom they could go for advice or treatment (see Chapter 6, Section 3 and above.). This suggests that they perhaps had a different outlook on health that goes beyond the vaccination issue (Sharma 1992; Astin 1998; Siahpush 1999; Hilton *et al* 2005). However it should be noted that many CAM users are also vaccinators. From my questioning of individual practitioners and a number of representatives of professional bodies, CAM professionals that follow a code of ethics will not actively advise their patients to avoid vaccinations, even if they themselves don't believe vaccinations are a good thing. But some might agree with their patients if they voice a willingness or intention to forego vaccinations (Turner 2003; SoH 2004).

The stress and anxiety experienced by new parents about the vaccination of their children, whether they choose to vaccinate or not is well reported (Evans *et al.* 2001; Hobson-West 2007; Leach 2007). In Leach's book "Vaccine Anxieties", the vaccination research used for discussion is the Poltorak research, as they worked together on this. This research first published in 2005, is based on 24 parents in the south of England. Focus groups were held to discover how parents discuss and decide on the MMR. They discovered a connection between active birthing, birth research and non vaccination, a link also present in my research. They also explain that several mothers talked about accepting the vaccinations because they were under

too much stress as young single parents to object: “vulnerability was a reason for vaccination” (Poltorak *et al.* 2005). They felt vulnerable and said that they needed the support of their health care practitioner which they thought might be withheld if they didn’t comply with the mass vaccination practice.

In my research, there were two lone parent families among the respondents who did not feel that need to “tow the line”; they felt that protecting their child from the harm of vaccination was more important than having the doctor’s approval.

c. The role of public health in society

Much of the research undertaken in the UK and the USA on parents’ views of vaccinations has been based on the premise that vaccination is something to be fostered and expanded (see chapter 2 sec 4). From the bio-medical perspective this is perfectly logical as the assumption is that these vaccinations are a public health service beneficial to both individual and society.

This raises question about legitimacy and social control. How has it come about that the public health system has the remit, and the power, to tell its citizens what is good for them and what drugs they should be taking? What long history lies behind this? Historically, medicine and religion, once united, had separated by the time of the age of enlightenment (see chapter 1). The decline of organised religion with its influence on moral constraints and behavioural convention left society in disarray and without moral guidance and control (Pickering 1994). The role of providing moral guidance and social control, previously in the care of clerics has been taken over by the public health sector (Dew 2007). If public health has indeed become a vehicle for moral regulation as suggested by Dew, this would explain why we do not need the law to enforce vaccination in the UK, as is the case in some other countries.

This Durkheimian concept may help to explain how it is that so many people conform to the practice of vaccination, although not without anxiety or concern as noted above. Historically, as discussed in chapter one, the main objection to vaccination initially related to bodily interference; it was experienced as a rights issue not a medical one (Lancet 1888; Durbach 2005). This was before public health had become what it is now, before public health performed a “moral regulatory function” to use Dew's words. In this context, it is interesting to examine what respondents in my study thought, as their choices can be seen as countering both public and medical opinion about what is best for your child's health. For the majority of the respondents in my study this aspect of the vaccination protocol, the issue of rights, was not an issue at all. They seemed to expect that public health had a moral duty to keep people healthy, it was just that they disagreed with public health's understanding of health and they disagreed with the claims of the science of vaccination. They seemed to have opted out in order to promote the health of their children, given their own understandings and belief system.

d. Health beliefs that don't fit in with public health policy

The examination of health beliefs has been of central concern in medical sociology and anthropology. However, since biomedical science has become fundamental to the practice of medicine and the policy for evidence based medicine has become so central; reflexivity in medical practice has necessarily become more limited. The idea of “health beliefs” does not fit very comfortably in a world where scientific evidence is the primary driver. Health beliefs are frequently labelled and framed as erroneous beliefs that need to be changed in order to solve a health inequality or problem (Good 1994). It is assumed that biomedical healthcare is

based on science which has been proved to be correct. This was felt by some of my respondents as a kind of fundamentalist disapproval of their own belief in what constitutes health. The respondents gave a variety of reasons and opinions about why and how they decided not to have their children vaccinated. Although they differed in the zealousness of their beliefs and in the strategies they used for coping with the consequences of their actions, the reasons they gave for not vaccinating were on the whole quite similar. Their primary intention for not vaccinating was their belief that by so doing they were enabling better health and a stronger immune system for their child - that they were enhancing their child's health and development. This was in some cases a radical choice to make which demanded much research and soul searching on the part of the parents, as noted above. These parents did not regard themselves as negligent, uninformed or selfish, as they said they were sometimes accused of being (see Chapter 4, 3, e and Chapter 5, 1, a.). For the wellbeing of their own child they have forfeited the comfort of being part of the norm by going against the status quo, by opposing the recommendations of their GP, but they did not do this without considerable thought. They researched the subject, and then made an informed choice, something strongly encouraged in modern health policy. Health, like religion, has a very intimate and personal dimension, some aspects of which may not be quantifiable or scientifically explainable (Sloan *et al.* 1999). What was noticeable was that the people interviewed for this research did not embrace biomedicine, but neither did they totally reject it - calling on it mainly for emergencies or serious illness. In tending to use alternative practitioners and self care, their life-world of health and illness would less likely sit comfortably with such an intervention as vaccination.

Another aspect of the vaccination policy which the respondents found difficult to accept was the way the vaccination programme is disseminated, from above down, perceived as a population levelling, medicalisation of the masses. To the more politically aware respondents this came across as patronising, old fashioned and unnecessary. They tended to think like consumers (Siahpush 1999). If they wanted vaccinations for their children, they said, they could ask their medical practitioner for them. Vaccine 'refusers', like the respondents, are sometimes classed as 'ignorant' or even 'subversive', for undermining the herd immunity aspect, for being responsible for the illness of others (Evans *et al.* 2001; Hobson-West 2007; Poltorak 2005; Rogers 1995) (and Chapter 4 and 6). This indicates more than anything else the amount of fear and anxiety there is in our society about disease and about people who are different, something these respondents directly experienced. It also indicates the complexity of the subject of herd immunity. Herd immunity is a concept that these respondents couldn't integrate into their understanding of their responsibility to their children or indeed into their understanding of community health in general. They just did not believe that herd immunity was a valid scientific concept, and gave sophisticated accounts of why they thought this.

The respondents had a faith in the innate health and capacity of the body to overcome, or deal with the consequences of any illnesses "life would throw at them". The concepts of fate and destiny were mentioned by two of the respondents as concepts to give meaning to illness should it ever occur (see Chapter 6, pg 144). They all believed that the vaccines could damage their child's health and compromise their child's immune system, vitality and mental health for the rest of its life.

There were those respondents who said that they felt that there were too many vaccinations and that all the chemicals and foreign proteins injected into the bodies of their children with vaccinations could not be a good thing in the long run (see Chapter 4, 3, e). They felt similarly about other medications and drug interventions. There were strong believers in the idea that “less is more” and “don’t fix something if it isn’t broke” There was a general worry amongst all the respondents, that as a nation we should be learning the lessons from the over prescribing of antibiotics and the emergence of super bugs such as MRSA and clostridium difficile. Medication was something they tried to avoid whenever possible, both for themselves and for their children and choosing to opt out of vaccinations was part of that lifestyle choice.

The media was also mentioned as having influence on the respondents’ attitude, feelings and experiences. TV, magazines, newspaper, the radio and the internet are powerful disseminators of vaccination news and the media touches everyone in society. We are all alerted to the latest panics, cures and scandals by the media. The subject of vaccinations is frequently in the news also, often framed commercially, as a press release from a vaccine provider or developer or as a political article promoting the work the government does for the health of the nation and the NHS. For example the article on May 8th, 2008, in the Guardian, “MP Proposes Jabs Link to School Place”, reported an interview with the Labour MP for Wakefield, Mary Creagh, who proposed that the government introduced mandatory vaccination on school entry for all primary school children. She was quoted in the article as saying, “Childhood vaccinations are as low as 11% in inner London and cases of measles and rubella are rising sharply”. She proposed mandatory vaccinations with the

reasoning that it would create equality in health care provision (Meikle 2008).

Precisely the kind of reasoning that my respondents were so anxious about and wanted so much to avoid. If they were forced to vaccinate their children, and if they refused, would their children be taken into care? Several of the parents had watched programmes on television, such as Panorama, about the MMR debate and were not at all happy with the way non-vaccinators were portrayed. The power of the media with its ability to cause panic was a real worry for some respondents. They explained that they researched for evidence themselves and did not take media accounts at face value, but nevertheless lived with the effects when they felt castigated as non-vaccinators.

Section 3. What has this study added?

This study adds depth and breadth to the research already conducted by others and places the understanding of a non-vaccination attitude in an historical context. In a society where informed consent remains a core value underpinning health intervention, it is important to understand the reasons behind the decision of those who choose not to vaccinate.

Other research has identified parents' concerns about vaccination also. Research done by Rogers and Pilgrim in 1995, (Rogers and Pilgrim 1995) showed that "non-compliers" as they were then called, weren't all ignorant about the science of vaccination and that there were parents who didn't want their children vaccinated. The research 5 years later by Evans et al in 2001 showed that parents who did have their children vaccinated also had misgivings about the safety and/or necessity of vaccinating healthy children. Poltorak uncovered groups of people who didn't believe in vaccinating and began to explore the politics of vaccination/non

vaccination in 2003 (Poltorak *et al.* 2007). Hobson West interviewed key members of organisations supporting people who don't vaccinate such as the Informed Parent, JABS, SoH, and others. Calling these groups "vaccine critical" groups that can be seen as either Radical or Reformist, she found that they reframed risk and trust and gained empowerment from taking personal responsibility for health decision-making (Hobson-West 2004,2007).

Hilton in Glasgow, working with focus groups, tested out people's responses to the MMR debate (Hilton *et al.* 2006,2007,2007a) as previously discussed, and Skea's research via an online discussion forum also exposed parents' worries and fears surrounding the MMR vaccine programme (Skea *et al.* 2008).

The research undertaken for this thesis adds weight to the body of knowledge around health beliefs and vaccination that highlights lay rationality as well as parental anxiety. The narrative approach taken here allows deeper meaning and grounds analyses in individual parents' understanding of who their child is and what constitutes health. It asks questions about responsibility, about faith and about child development. To these parents their decision to not vaccinate was not an oversight, not an error, but a thoughtful response embedded in their life-world. This will and does create tension within society which on the one hand emphasises informed choice and informed consent for medical procedures, yet on the other hand actively promotes a particular choice as the only rational one. More widely, this study perhaps highlights the need for openness, diversity, multiplicity, change and growth within our health care system and services.

Section 4. Possible Action and Future Research

One of the results of this research has been to raise awareness of other health beliefs and about the experiences of encountering the state supported biomedical model of healthcare by those people who hold other health beliefs. Although ethnicity wasn't looked at in this research, the outcomes may well inform policy working with other minorities, be they ethnic, cultural or religious in nature. As we are facing an increasingly unsettled world population, with large groups of people moving away from their country of origin for whatever reason, it is most likely that people with different health beliefs and practices will increase in number in the UK (Scheppers *et al.* 2006). Therefore the need for more openness and for a recognition of more diversity of opinion about health care measures will become more and more important. Although immigration is not a new occurrence in itself, our awareness of incomers and our wish to include immigrants and migrants in our health planning strategies is perhaps more intentional than it was in the past.

There is obviously much more to health service provision than the supply of drugs and medical interventions, demonstrated by the research described in Chapter 2 Section 4 of the thesis, undertaken in 2003 by Henderson, Millett and Thorogood in London (Henderson *et al.* 2008) within a community of 20,000 traditional Jewish people. This large community of people, which has been part of London for hundreds of years, is not served by the NHS as well as it could be because they have different health and lifestyle expectations and practices that are not incorporated into their local NHS provision. A community-based participatory research project (CBPR) could be undertaken with this community, or another similarly isolated but culturally unified group of people, with the purpose of learning from them and

listening to them to discover what their needs are, from their point of view. If researchers could hear what the researched believe, what they think and feel, and learn how they manage their health issues within their own community, it could inform Public Health how to develop the public health services to better serve them by being more inclusive and more diverse (Scheppers *et al.* 2006). At present both my own and other research shows that some medical services, the service of mass vaccination as explored in my research for example, fail to address the needs of people who do not believe in the NHS vaccination policy.

Another study which would help to expand on some of the new and difficult ideas brought up by the respondents in this research would be an observational study of unvaccinated children. A rough estimate based on the number of children in the UK, (about 12 million) (NationalStatistics 2009) and making an educated guess based on the level of uptake reported by GP practices (HealthProtectionScotland 2009) which puts the level at 92% on average, would identify the number of unvaccinated children in the UK at least 960,000 children. How many of these children are intentionally not vaccinated for health belief reasons? Some of the preliminary work for such an observational study might be able to explore this area and inform Public Health. The study itself could expand on many of the points brought up by respondents of the research reported in this thesis. Statements made by non and partial vaccinators such as: ‘unvaccinated children have less chronic illnesses’, or, ‘unvaccinated children have more energy’, or, ‘unvaccinated children are less likely to be diagnosed autistic’ could be explored in more depth and tested. Such a research project could also be instrumental in uncovering other health beliefs and practices and gaps in NHS provision.

The results of this research also highlighted the possible influence of alternative and complementary medical professionals on their patients' health beliefs particularly on their non-uptake of vaccinations. Some research in this area has been carried out particularly in Canada with Chiropractors, but only in the form of questionnaires, not as an in-depth research project. This might be further explored by researching the ontology of alternative and complementary therapists on vaccination, in particular homeopaths, chiropractors and homeopathic doctors. This would enrich the sociological debate and the epistemology of vaccinations; as would a research project, researching the views of medical health professionals -GPs, practice nurses - those who provide vaccinations to the public and have to deal with controversies in science and also with parental anxieties and concerns.

To answer the need of an increasing number of parents (Leach and Fairhead 2007) and mentioned by several respondents of this research also, a double blind placebo controlled clinical trial might provide some answers to serious questions raised by a number of the respondents, namely: what is the effect of multiple vaccinations on a child? What kinds of DNA mutations, if any, are engendered by the practice of vaccination? Is there any long term damage done to the brain, or to the immune system? Each individual vaccine is tested for safety by the manufacturers before a license is approved (Nalin 2002). But no one seems to have carried out research on the potential cumulative effect of the many vaccinations and repeated vaccinations now recommended for children.

To be able to gain more understanding about parents' decision-making and about health beliefs, a more in-depth approach such as that used in ethnography, together with a conversational interview or a series of interviews at the home of non

vaccinating respondents might be more insightful and could uncover more information about what makes someone have such strong health beliefs and act on them by refusing vaccination (Reeves 2008). Although elements of ethnographic research and of interpretive biography (Denzin 1989) were used in a very small degree in the methods for my research, more use could have been made of this type of interviewing had there been fewer respondents to research.

My study was deliberately limited to in-depth interviews with non vaccinating parents and with one non parent adult. Two parents had allowed their previous child to be vaccinated and then changed their minds about the procedure for their subsequent child. One parent had some vaccinations for her child but not others. Undertaking interviews with parents who had had reservations but then decided to vaccinate anyway may have provided an alternative perspective on health beliefs and on how and why people make such a difficult decision. This is an approach that could be developed through future work.

A strongly held opinion by some of the respondents in my research was that vaccination studies should be published and openly accessible to parents, perhaps on a vaccination website or within the GP surgeries where the vaccines are delivered. For an increasing number of patients, parents, customers, people, it is no longer the appropriate to “just follow the herd” and vaccinate because everyone else does it (Stevenson *et al.* 2005). Parents have a right and a need to see research done on vaccine safety. This must be independent research; parents told me that they did not trust trials done by the pharmaceutical industry with the aim of acquiring a licence, no matter how rigorous and scientific these may be. Because the vaccines are administered by health workers, the packaging and leaflet inserts are never given to

parents. The parents in my study have told me that they need to have seen this information and much more information before they attend with their babies/children, so they can be prepared for vaccinations having made an informed choice (Fine 1993)(see chapter 4 section 2 and 3). If vaccines are tested on animals or attenuated in animals or if animals have been used in any way in their manufacture, parents need to know this, given that they might be Vegan, or Kosher, or against animal testing. The fact that the GP practice gets paid for each vaccination administered undermines the GPs credibility to giving impartial advice, according to my respondents. Openness and honesty will help enormously to take away fear and anxiety engendered by the poor information that the respondents described (see chapter 4 section 2 and 3). Patients' rights and freedom need to be respected, even if they are not all understood.

The system of childhood vaccination is complex and all parents need time to both study and assimilate information or to decide to go ahead and trust the health professionals. The first few months after delivering a baby is not the best time in a parent's life to be studying complex scientific papers and making important decisions about their child's future health. Vaccinations could be part of pre natal education, rather than post natal health intervention strategies. They might even be studied within health and science classes in high school (Edwards 2005; Poltorak 2007).

In an age of openness, diversity and accountability, the opinions and attitudes of my respondents and people like them, could perhaps be better listened to. A health system for the people must also be 'of' the people as Leach explains:

“A health system is not just a set of infrastructures for delivering a set of technical services and associated expert knowledge. Rather, it is embedded within a set of moral and social orders and a set of bodily and wider political reflection. It is

this wider interpretive and experiential complex that shapes parental thinking and practice” (Leach 2007).

The ‘*wider interpretive and experiential complex*’ that Leach mentions, was for my respondents, a life style and philosophical or religious issue and not a problem to be solved by medical or pharmaceutical means.

The rift experienced by the respondents in this research between the health service and the general public on the one hand and their own ambitions for the health and wellbeing of their children on the other, was not just experienced as emotionally difficult, it also created a potential vacuum in health service provision altogether. These parents may not feel able to contact their GP when their child is ill, due to the fact that they feel that they have been ostracised for their vaccination stance. To address this problem some participatory research projects could be undertaken within largely non vaccinated families and communities. To create a dialogue between vaccinators and non vaccinators and between health workers and non vaccinators may go a long way to building bridges between these groups and repair communication and health care provision opportunities.

There have been major shifts, twists and turns all along the way for all participants in the vaccination arena which pose more questions and make the subject more complicated than ever. Questions such as:

How can public health better promote equality in health care? Are mass childhood vaccinations a necessary medical intervention for a healthy population? Are GP surgeries the best distributors of vaccinations? How can people become more involved their own and in the public health care strategies?

Many more questions exist; questions for GPs and allied health professionals, for the media, for pharmaceutical companies, the government and for parents - for all the

stakeholders in the world called Vaccinations. The debates about vaccination will continue. This thesis' contribution was to explore the beliefs and practices of those who actively choose not to vaccinate and has helped to generate some answers to these difficult questions.

The sociology of vaccination is a young field, yet it can be instrumental in revealing the epistemology of health and illness and of medicine as we know it today.

References

Bibliography

- Ackerknecht, E. H. (1982). A Short History of Medicine. Baltimore, John Hopkins University Press.
- Agger, B. (2002). "Sociological Writing in the Wake of Postmodernism." Cultural Studies: Critical Methodologies 2(4): 436.
- Alderson, P., B. Mayall, S. Barker, J. Henderson and B. Pratten (1997). "Childhood immunization: Meeting targets yet respecting consent." Eur J Public Health 7(1): 95-100.
- Allsop, J. (1984). Health Policy and the National Health Service, Longman.
- Anderson, R. M. (1991). Infectious diseases of humans : dynamics and control. Oxford, Oxford University Press.
- Andrews, N. (2006). "Vaccine Scares." Significance 3(4): 158-161.
- Anti-Vaccinator, C.-o. a. (1871). "Editorial." Co-operator and Anti-Vaccinator: 323.
- Astin, J. A. (1998). "Why Patients Use Alternative Medicine: Results of a National Study." JAMA 279(19): 1548-1553.
- Atrasheuskaya, A. V., M. V. Kulak, A. A. Neverov, S. Rubin and G. M. Ignatyev (2006). "Measles cases in highly vaccinated population of Novosibirsk, Russia, 2000-2005." Vaccine .
- Baker, J. P. (2003). "The pertussis vaccine controversy in Great Britain, 1974–1986." Vaccine 21(25-26): 4003-4010.
- Bakx, K. (1991). "The "Eclipse" of Folk Medicine in Western Society." Sociology of Health and Illness 13(1): 20-38.
- Barbour, R. S. (2006). Introducing qualitative research : a student guide to the craft of doing qualitative research. London, Sage.
- Bashford, A. and C. Hooker, Eds. (2001). Contagion: historical and cultural studies. London, Routledge.
- Bazin, H. (2001). "The ethics of vaccine usage in society: lessons from the past." Current Opinion in Immunology 2001(13): 505-510.
- BBC. (2000). "Vaccine compensation increase." Health, 2008.
- Beck, U. (1992). Risk Society: Towards a New Modernity. London, Sage.

- Bedford, H. and D. Elliman (2003). "Press: MMR: the onslaught continues." BMJ **326**(7391): 718-.
- Berg, J. W., Applebaum, Paul, S., Parker, Lisa S., Lidz, Charles W. (2002). Informed Consent: Legal Theory and Clinical Practice. Oxford, Oxford University Press.
- Bloor, M., McIntosh, J. (1990). Surveillance and Concealment: a Comparison of Techniques of Client Resistance in Therapeutic Communities and Health Visiting. Readings in Medical Sociology. S. Cunningham-Burley, McKeganey, N. London, Routledge.
- Blume, S. and I. Geesink (2000). "Vaccinology: An Industrial Science?" Science as Culture **9**(1): 41-72.
- BMA. (2008). "Vaccination Payments." Retrieved 28 May, 2008.
- Bollet, J. A. (1987). Plagues & Poxes. The Rise and Fall of Epidemic Disease. New York, Demos Publications.
- Bosanquet, W. C. and J. Eyre (1904). Serums, Vaccines and Toxines. London, Cassell and Company.
- Bower, H. (1998). "Link with bowel disease fuels controversy over vaccine." BMJ **316**(7133): 723c-.
- Brock, T. D. (1988). Robert Koch : a life in medicine and bacteriology. Madison Wisconsin, Science Tech Publishers.
- Brown, P. S. (1991). " Medically qualified naturopaths and the General Medical Council,." Medical History **35**(1): 20.
- Burgess, D. C., M. A. Burgess and J. Leask (2006). "The MMR vaccination and autism controversy in United Kingdom 1998-2005: Inevitable community outrage or a failure of risk communication?" Vaccine **24**(18): 3921-3928.
- Burgess, M. (1994). "Homeopathy and vaccination." Lancet **344**(1168).
- Cambrosio, A., D. Jacobi and P. Keating (1993). "Ehrlich's 'beautiful pictures' and the controversial beginnings of immunological imagery." Isis(84): 662-699.
- Cassell, E. J. (1982). "The Nature of Suffering and the Goals of Medicine." New England Journal of Medicine(306): 634-645.
- Chaitow, L. (1987). "Vaccination and Immunization: Dangers, Delusions, and Alternatives." Essex, England, CW Daniel Company Ltd.
- Charmaz, K. (2006). Constructing Grounded Theory. London, Sage.
- Charmaz, K. (2007). The Sage handbook of grounded theory. London, Sage.

- Clifford, C. G. (1998). Ethics and Politics in Qualitative Research. The Landscape of Qualitative Research. N. K. Denzin and Y. S. Lincoln. London, Sage: 208-245.
- Cohon, H. (1998). "Interview with IG." Science as Culture 8(2).
- Colgrove, J. (2006). State of Immunity. Berkeley, California, University of California Press.
- Cooter, R., Pickstone, John., Ed. (2003). Companion to Medicine in the Twentieth Century. Routledge World Reference. London, Taylor & Francis.
- Coulter, H. L. and B. L. Fisher (1985). DPT, a shot in the dark, Harcourt.
- Creswell, J. W., W. E. Hanson, V. L. Clark and A. Morales (2007). "Qualitative Research Design." The Counseling Psychologist 35(2): 236-264.
- Cunningham-Burley, S. (1990). Mother's beliefs about and perception of their children's illnesses. Readings in Medical Sociology. S. Cunningham-Burley and N. McKeganey. London, Routledge.
- Cunningham-Burley, S. and N. P. Mc Keganey, Eds. (1990). Readings in Medical Sociology. London Tavistock/Routledge.
- Curtis, S. (1994). Handbook of homoeopathic alternatives to immunisation Saffron Walson, Winter Press.
- Denzin, N. K. (1989). Interprative biography. London, Sage.
- Denzin, N. K. (2003). Performance ethnography: Critical pedagogy and the politics of culture. Thousand Oaks, CA, Sage.
- Denzin, N. K. and Y. S. Lincoln (1998). The Landscape of Qualitative Research. Theories and Issues. London, Sage.
- Dew, K. (1999). "Epidemics, panic and power: representations of measles and measles vaccines." Health 3(4): 379-398.
- Dew, K. (2007). "Public health and the cult of humanity: a neglected Durkheimian concept." Sociology of Health & Illness 29(1): 100-114.
- DHS. (2008). "Informed Consent." www.nhs24.com Retrieved 21 May 2008, 2008.
- Dobson, R. (2003). "Media misled the public over the MMR vaccine, study says." BMJ 326(7399): 1107-a-.
- Douglas, M. (1992). Risk and blame: essays in cultural theory. London, Routledge.
- Doyal, L. (2001). "Informed consent: moral necessity or illusion?" 10(1): i29-33.

- Doyle, L. (1995). What Makes Women Sick. Gender and the Political Economy of Health. London, Macmillan Press Ltd.
- Durbach, N. (2005). Bodily Matters. London, Duke University Press.
- Edwards, N. P. (2005). Birthing autonomy : women's experiences of planning home births. Abingdon, Routledge.
- Eisenberg, L. (1977). "Disease and Illness: distinction between professional and popular ideas of sickness." Culture, Medicine and Society 1(1): 9-23.
- Elliot, J. (2005). Using Narrative in Social Research Qualitative and Quantitative Approaches. London, Sage.
- Engel, G. L. (1981). The Need for a New Medical Model: a Challenge to Bio-medicine. Concepts of Health and Disease: Interdisciplinary Perspectives. A. L. Kaplan, Engelhardt, H.T., McCartney, J.J. London, Addison Wesley.
- Esterberg, K. G. (2002). Qualitative Methods in Social Research. New York, McGraw-Hill.
- Evans, M., Stoddart, H., Condon, L., Freeman, E., Grizzell, M., Mullen, R. (2001). "Parents' perspectives on the MMR immunisation: a focus group study." Br J Gen Pract. 51(472): 904-10.
- Executive, S. (2008). National Care Standards: Hospice Care. D. o. Health, Scottish Exec.
- Faden, R. B., Tom. King, Nancy, (1986). A History and Theory of Informed Consent. New York City, Oxford University Press.
- Fichman, M., Keelan, Jennifer E. (2007). "Resister's logic: the anti-vaccination arguments of Alfred Russel Wallace and their role in the debates over compulsory vaccination in England, 1870-1907." Studies in History and Philosophy of Biological and Biomedical Sciences 38: 585-607.
- Finch, J. (1984). 'It's great to have someone to talk to':the ethics and politics of interviewing women. Social Researching. C. Bell and H. Roberts. London, Routledge.
- Fine, P. (1993). "Herd Immunity: History, Theory, Practice." Epidemologic Reviews 15(2): 265-298.
- Fitzgerald, T., D. Jourdan and L. Sholtz (2006). "Influenza: Lessons Learned from an Outbreak, Post-Exposure Prophylaxis and Vaccination Campaigns." American Journal of Infection Control 34(5): 88-102.
- Flint, G. A. (2001). Emotional freedom techniques for dealing with emotional and physical distress. Vernon, BC Canada, NeoSolTerric Enterprises.

- Folb, P. I., Bernatowska, Ewa, Chen, Robert, et al. (2004). "A Global Perspective on Vaccine Safety and Public Health: The Global Advisory Committee on Vaccine Safety." Am J Public Health **94**(11): 1926-1931.
- Fombonne, E. and S. Chakrabarti (2001). "No Evidence for A New Variant of Measles-Mumps-Rubella-Induced Autism." Pediatrics **108**(4): e58-.
- Foucault, M. (1974). The Birth of Social Medicine. London, Penguin Press.
- Foucault, M. (1975). The Birth of the Clinic. New York, Pantheon.
- Freeman, P. and A. Robbins (2002). "The Elusive Promise of Vaccines." The American Prospect(4): 80-90.
- Freeman, R. (1992). The idea of prevention: A critical review. Private Risks & Public Dangers. S. Scott, Williams, G., Platt, S., Thomas, H. Aldershot, Avebury.
- Funtowicz, S. O. and J. R. Ravetz (1992). "The good, the true and the post-modern." Futures(24): 963-976.
- Gabe, J. (1995). Medicine, health and risk: Sociological approaches. Oxford, Blackwel.
- Geier, D. and M. Geier (2002). "The True Story of Pertussis Vaccination: A Sordid Legacy?" J Hist Med Allied Sci **57**(3): 249-284.
- Giddens, A. (1991). Modernity and Self-Identity. Self and Society in the late Modern Age. Cambridge, Polity Press.
- Glaser, B. (1992). Basics of Grounded Theory Analyses Emergence vs Forcing. Mill Valley, CA, Sociology Press.
- Glaser, B. and A. Strauss (1967). The Discovery of Grounded Theory: Strategies for qualitative research. New York, Aldine Pub. Co.
- Glaser, B. and A. Strauss (1977). The discovery of grounded theory: Strategies for qualitative research, Aldine.
- Goebel, W. and M. Gloeckler (1988). Guide to Child Health. Sring Valley, Anthroposophic Press.
- Good, B. J. (1994). Medicine, rationality, and experience: an anthropological perspective. New York, Cambridge University Press.
- Gov. (2008). "Immunization: You call the shots."
http://www2.cdc.gov/nip/isd/ycts/mod1/courses/genrec/10300.asp?student_id
≡ Retrieved 17/08/08, 2008.
- Government, S. (2009). Health and Community Care, Scottish Parliament.

- Graham, H. (1984). Women, Health and Family. Brighton, Wheatsheaf Books.
- Graham, H. (1985). Providers, negotiators and mediators: women as hidden carers. Women, Health and Healing. E. a. O. Lewin, V. London, Tavistock.
- Gray, B. H. (1978). "Complexities of Informed Consent." **437**(1): 37-48.
- Gray, D. (2002). "A role for antigen in the maintenance of immunological memory." Nature Reviews **2**(January 2002): 60-65.
- Greco, M. (1993). "Psychosomatic subjects and the 'duty to be well' " Economy and Society **22**(3): 357-372.
- Greene, M. a. D., David (2004). The Philosophy of Biology: An Episodic History Cambridge, Cambridge University Press.
- Gullion, J., Smartt, et al. (2008). "Deciding to Opt Out of Childhood Vaccination Mandates." Public Health Nursing **25**(5): 401-408.
- Gunn, T. (1995). Mass Immunization. East Grinstead, Helios Press.
- Haggard, H. (1929). Devils, drugs and doctors : the story of the science of healing from medicine man to doctor. London Heinemann Medical.
- Haggard, H. (1934). The Doctor in History. London, Oxford University Press.
- Halsey, N. A., S. L. Hyman and P. the Conference Writing (2001). "Measles-Mumps-Rubella Vaccine and Autistic Spectrum Disorder: Report From the New Challenges in Childhood Immunizations Conference Convened in Oak Brook, Illinois, June 12-13, 2000." Pediatrics **107**(5): e84-.
- Hardey, M., Ed. (1998). The Social Context of Health. Health Psychology. Buckingham, Open University Press
- Hardon, A. and S. Blume (2005). "Shifts in global immunisation goals (1984-2004): unfinished agendas and mixed results." Social Science & Medicine **60**(2): 345-356.
- Harrington, P. M., C. Woodman and W. F. Shannon (2000). "Low immunisation uptake: Is the process the problem?" J Epidemiol Community Health **54**(5): 394-.
- Head, C. (2005). An Educated Decision. One approach to the vaccination problem using homeopathy. Saffron Waldon, Health Publishing.
- HealthProtectionScotland. (2009). "Vaccines." Protecting Scotland's Health, 2009.
- Heininger, U. (2006). "An internet-based survey on parental attitudes towards immunization." Vaccine **24**: 6351-6355.

- Heller, J. (2008). The Vaccine Narrative. Nashville, Vanderbilt University Press.
- Helman, C. G. (1988). *Psyche, Soma, and Society : The Social Construction of Psychosomatic Disorders*. Biomedicine Examined. M. a. G. Lock, Deborah. London, Kluwer Academic Publishers.
- Henderson, L., C. Millett and N. Thorogood (2008). "Perceptions of childhood immunization in a minority community: qualitative study." J R Soc Med **101**(5): 244-251.
- Henderson, R., K. Oates, H. Macdonald and W. Smith (2004). "General practitioners' concerns about childhood immunisation and suggestions for improving professional support and vaccine uptake." Commun Dis Public Health **7**(4): 260-6.
- Henry, R., K. Ogle and L. Snellman (1987). "Preventive medicine: physician practices, beliefs, and perceived barriers for implementation." Family Medicine **19**(2): 110-113.
- Hilton, S. (2005). Parental perceptions of childhood immunisation in the context of the MMR controversy. MRC unit. Glasgow, Glasgow. **PhD**: 254.
- Hilton, S., K. Hunt, M. Langan and M. Petticrew (2009). "Reporting of MMR evidence in professional publications (1988-2007)." Arch. Dis. Child.
- Hilton, S., K. Hunt and M. Petticrew (2007). "Gaps in parental understandings and experiences of vaccine-preventable diseases: a qualitative study." Child: Care, Health and Development **33**(2): 170-179.
- Hilton, S., Pettigrew, M., Hunt, Kate (2007). "Parents' champions vs vested interests: Who do parents believe about MMR? A qualitative study." BMC Public Health **7**(42).
- Hirschler, B. (2002). "Vaccine Renaissance Outpaces Sickly Drug Industry ", 2008.
- Hume-Rothery, M. (1871). "Editorial." Co-operator and Anti-Vaccinator.
- Illich, I. (1976). Limits to Medicine. London, Marion Boyars.
- Illich, I. (1977). Limits to medicine : medical nemesis ; the expropriation of health Harmondsworth, Penguin.
- Jackson, T. (2003). "MMR: more scrutiny, please." BMJ **326**(7401): 1272-.
- Jaeger, C., Renn, O., Rosa, E., Webler, T (2001). Risk, and Uncertainty, and Rational Action. London, Earthscan.
- Jamison, A. (2001). The making of green knowledge: environmental politics and cultural transformation. Cambridge, Cambridge University Press.

- Janeway, C. A. (1992). "The immune system evolved to discriminate infectious nonself from noninfectious self." Immunology Today **13**(1): 11-16.
- Jenner, E. (1798). An Inquiry into the Causes and Effects of Variolae Vaccinae, a Disease Discovered in Some Western Counties of England. London, Sampson Law.
- Jenner, E. (1799). Further observations on the variol vaccin, or cow pox. London.
- Jenner, E. (1800). An inquiry into the causes and effects of the variol vaccin, a disease discovered in some of the western counties of England, ... and known by the name of the cow pox. London.
- Jones, A. (2005). "Vaccination .com." Retrieved 20/11/2007, 2007, from www.prisonplanet.com.
- Kew, O. M., P. F. Wright, V. I. Agol, F. Delpeyroux, H. Shimizu, N. Nathanson and M. A. Pallansch (2004). "Circulating vaccine-derived polioviruses: current state of knowledge." Bulletin of the World Health Organization **82**: 16-23.
- Kim, B. (2006). Must see video on Vaccination dangers, <http://drbenkim.com/vaccination-hidden-dangers.htmr>.
- Kirkmayer, L. J. (1988). Mind and Body as Metaphors: Hidden Values in Biomedicine. Biomedicine Examined. Culture, Illness and healing. M. a. G. Lock, Deborah. London, Kluwer Academic Publishers
- Kitzinger, J. (1994). The methodology of Focus Groups: the importance of interaction between research participants. **16**: 103-121.
- Kitzinger, S. (2006). Birth Crisis. Abingdon, Routledge.
- Kitzinger, S. (2007). The Politics of Birth. Amsterdam, Elsevier.
- Kmietowicz, Z. (2001). "Separate vaccines could endanger children." BMJ **323**(7315): 711b-.
- Kmietowicz, Z. (2007). "MMR controversy has left parents emotionally scarred, study finds." BMJ **334**(7596): 715-d-.
- Lambert, R. J. (1963). Sir John Simon 1816-1904 and English Social Administration. London, Macgibbon and Kee.
- Lancet (1888). "Vaccination and its Opponents." The Lancet **131**(3367): 484-484.
- Lancet (1897). "Statistics of Smallpox and Vaccination." The Lancet **149**(3852): 1763-1764.
- Lancet (1907). "The Government and Vaccination." The Lancet **170**(4376): 98-98.

- Landsteiner, K. (1962). The Specificity of Seriological Reactions. New York, Dover.
- Le Fanue, J. (1999). The Rise & Fall of Modern Medicine. London, Little Brown and Co.
- Leach, M. and J. Fairhead (2007). Vaccine Anxieties. London, Earthscan.
- Leask, J. and P. McIntyre (2003). "Public opponents of vaccination: a case study." Vaccine **21**(32): 4700-4703.
- Lietz, C. A., Langer, Carol L., Furman, Rich (2006). "Establishing Trustworthiness in Qualitative Research in Social Work: Implications from a Study Regarding Spirituality." Qualitative Social Work **5**(4): 441-458.
- Lippman, A. (2008). "Human papillomavirus (HPV) vaccination and the development of public policies." J Epidemiol Community Health **62**(7): 570-571.
- Lofland, J., & Lofland, L. (1995). Analyzing Social Settings: a guide to qualitative observation and analyses 3rd edition. London, Wandsworth Publishing Company.
- Luhman, N. (1993). Risk: A Sociological Theory. New York, Aldine de Gruiter.
- Lupton, D. (1994). Medicine as Culture: Illness, Disease and the Body in Western Societies. London, Sage.
- Lupton, D. (1999). Risk. London, Routledge.
- Madsen, K. M., A. Hviid and M. Vestergaard (2002). "A Population-Based Study of Measles, Mumps, and Rubella Vaccination and Autism." The New England Journal of Medicine **347**: 1477-1482.
- Martin, E. (1987). The Woman in the Body. Boston, Beacon.
- Martin, E. (1994). Flexible Bodies; the role of immunity in American culture from the days of Polio to the age of Aids. Boston, Beacon Press.
- Mason, J. (2006). "Mixing methods in a qualitative driven way." Qualitative Research **6**(1): 9-25.
- Mason, T. (2001). Stigma and Social Exclusion in Healthcare London, Routledge.
- Mauthner, N. and A. Doucet (1998). Reflections on voice-centered relational method: analysing maternal and domestic voices. Feminist Dilemmas in Qualitative Research: public knowledge and private lives. J. a. E. Ribbens, R. London, Sage. **1929-1931**.
- McKeown, T. and C. Lowe (1966). An introduction to social medicine Oxford Blackwell Scientific.

- McTaggart (1998). Vaccination Bible. London, What Doctors Don't Tell You.
- Mead, G. H., Ed. (1964). Scientific Method and the Individual Thinker. Mead Selected Writings. New York, Bobbs-Merrill Co.
- Meikle, J. (2008). MP Proposes Jabs Link to School Place. Educatioin Guardian. Manchester.
- Miles, A. (1991). Women, Health and Medicine. Buckingham, Open University Press.
- Miller, E. (2002). "MMR Vaccine: Review of Benefits and Risks." Journal of Infection **44**(1): 1-6.
- Mishler, E. G. (1986). Research Interviewing: context and narrative. Cambridge MA, Harvard University Press.
- Mitchell, R. G. J. (1993). Secrecy and Fieldwork. Newbury Park, CA, Sage.
- Morris, Z. S. C., Lind Rosenstrom. Dawson, Sandra. Garside, Pam, Ed. (2005). Policy Futures for UK Health. Abingdon, Radcliffe Publishing and The Nuffield Trust.
- Moscovitz, R. (1988). The Case Against Immunizations,. Atlanta, American Institute of Homeopathy,.
- Murphy, K. T., Paul. Walport, Mark. [et al..] (2008). Janeway's immunobiology. New York Garland Science.
- Nalin, D., R. (2002). "Evidence based vaccinology." Vaccine **20**: 1624-1630.
- NationalStatistics. (2009). "Population demographics." Retrieved 12.6.2009, 2009.
- NCJDSU). (2008). "The National Creutzfeldt-Jakob Disease Surveillance Unit (NCJDSU)." 2008.
- Nettleton, S. (1995). The Sociology of Health and Illness. Cambridge, Polity Press.
- Nettleton, S. (2006). The Sociology of Health and Illness 2nd edition. Cambridge, Polity Press.
- New, S. and M. Senior (1991). "'I don't believe in needles': Qualitative aspects of a study into the uptake of infant immunisation in two English health authorities." Soc. Sci. Med. **33**(4): 509-518.
- NHS. (2008). "Immunisation the safest way to protect your child." NHS information web pages Retrieved 02/06/08, 2008.
- Nicholson, R. H. (1996). "Old World News: U.K. Moves toward Compulsory Vaccination." The Hastings Center Report **26**(2): 4-4.

- Nystrom, K., Ohrling, Kerstin. (2004). "Parenthood experiences during the child's first year: literature review." Journal of Advanced Nursing **46**(3): 319-330.
- Oakley, A. (1974). The Sociology of Housework. Oxford, Martin Robertson.
- Oakley, A. (1981). Interviewing women: a contradiction in terms. Doing Feminist Research. H. Roberts. London, Routledge and Kegan Paul.
- Oakley, A. (1993). Essays on Women Medicine & Health. Edinburgh, edinburgh University Press.
- Osherson, S. and A. Singham (1981). The Machine as Metaphor. Social Context of Health, Illness and Patient Care. E. Mishler, Mishler, G., et al. New York, ambridge University Press: 218-249.
- Pakulski, J. (2009). Postmodern Social Theory. The new Blackwell companion to social theory B. Turner. Malden, Mass, Wiley-Blackwell.
- Pasteur, L. C., Roux (1881). "De l'attenuation des virus et de leur retore a la virulence." Comptes Rendus des Seances de L'Academie des Sciences **92**: 430-435.
- Patton, M. Q. (1990). Qualitative Evaluation and Research Methods (2nd ed.). Newbury Park, CA, Sage Publications, Inc.
- Paul, W. E., Ed. (1999). Fundamental Immunology. Philadelphia, Lippincott-Raven.
- Pellegrino, E. D. (1998). "What the Philosophy of Medicine IS." Theoretical Medicine and Bioethics(19): 315-336.
- Percival, S. S. (2000). "Use of echinacea in medicine." Biochemical Pharmacology **60**(2): 155-158.
- Pickering, W. S. F., Ed. (1994). Durkheim on religion. Atlanta, Ga., Scholar Press.
- Plotkin, S. (1998). Interview with the authors. S. Blume. Paris, Science as Culture.
- Poltorak, M., M. Leach, J. Fairhead and J. Cassell (2005). "'MMR talk' and vaccination choices: An ethnographic study in Brighton." Social Science & Medicine **61**(3): 709-719.
- Poltorak, M., Leach, Melissa., Fairhead, James. (2007). Body, Body Politic and Vaccination in the UK. Vaccination Anxieties. M. F. Leach, James. London, Earthwatch.
- Porter, R., Ed. (1996). Cambridge illustrated history of medicine. Cambridge, Cambridge University Press,.
- Porter, R., Ed. (1996). What is Disease? The Cambridge Illustrated History of Medicine. Cambridge, Cambridge University Press.

- Portier P, R., C. (1902). "De l'action anaphylactique de certains venins." Comptes Rendus des Seances de la Societe de Biologie et des Filials **54**: 170-172.
- Punch, K. (1998). Introduction to Social Research. . . London, Sage.
- Punch, K. (2005). Introduction to Social Research: quantitative and qualitative approaches. London, Sage.
- Racine, A. D. and T. J. Joyce (2007). "Maternal education, child immunizations, and public policy: Evidence from the US National Immunization Survey." Social Science & Medicine **65**(8): 1765-1772.
- Ramon, G. (1939). "William Hallock Park: an Eminent Microbiologist and a Great American Public Health Officer (1863-1939)." J Immunol **37**(3): 179-183.
- Rapp, R. (1998). "Refusing Prenatal Diagnosis: The Meaning of Bioscience in a Multicultural World." Science, Technology & Human Values **23**(1): 45-70.
- Rapp, R. (2000). Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America London, Routledge.
- Razzell, P. (1977). Edwards Jenner's Cowpox Vaccine: The History of a Medical Myth. Sussex, Caliban Books.
- Renzetti, C. M. a. L., Raymond M. (1993). Researching Sensitive Subjects. London, Sage Publications.
- Ribbens, J. (1994). Mothers and their children : a feminist sociology of childrearing. London, Sage.
- Roberts, H., Ed. (1992). Women's Health Matters. London, Routledge.
- Rogers, A. and D. Pilgrim (1995). The risk of resistance: perspectives on the mass childhood immunisation programme. Medicine, Health and Risk: Sociological Approaches. J. Gabe. Cambridge Blackwell. **54**.
- Romm (2001). Vaccinations: A Thoughtful Parent's Guide - How to Make Safe, Sensible Decisions About the Risks, Benefits and Alternatives. Rochester Vermont, Healing Arts Press.
- Rosa, E. A. (1998). "Metatheoretical Foundations for Post-Normal Risk." Journal of Risk Research **1**(1): 15-44.
- Rosen, G. (1958). A History of Public Health. New York, MD Publications.
- Saks, M. (2005). Medicine and Complementary Medicine Challenge and change. Medical Sociology. Major themes in health and social welfare. G. Scambler. Abingdon, Oxon, Routledge.

- Salmon, D. A., Teret, Stephen P, MacIntyre , C Raine , Salisbury, David, Burgess, Margaret A, Halsey, Neal A (2006). "Compulsory vaccination and conscientious or philosophical exemptions: past, present and future." The Lancet **367**(02/04): 436-42.
- Samad, L., N. Butler, C. Peckham and H. Bedford (2006). "Incomplete immunisation uptake in infancy: Maternal reasons." Vaccine **24**(47-48): 6823-6829.
- Santino, J. (1985). "On The Nature of Healing as a Folk Event." Western Folklore: 153-167.
- Saunders, C. (1981). Hospice: The Living Idea. London, Edward Arnold.
- Schreibner, V. (1993). Vaccination a Medical Assault on the Immune System. Maryborough, Victoria, Australia, Australian Print Group.
- Scott, S., Ed. (1992). Private risks and public dangers. Explorations in Sociology. Aldershot, Avebury.
- Sharma, U. (1992). Complementary Medicine Today: Practitioners and Patients. London, Routledge.
- Shaw, I. and L. Woodward (2004). Constructing Risk: Rumour as a Resource for Medical Sociology. Construction of Health and Illness: European Perspective. I. Shaw and K. Kappinen. Aldershot, Ashgate: 16-26.
- Siahpush, M. (1999). "A critical review of the sociology of alternative medicine: research on users, paractitioners and the orthodoxy." Sage Publications **4**(2): 159-178.
- Sigerist, H. E. (1944). Civilization and disease. Ithaca ; New York, Cornell University Press.
- Silverstein, A. (1989). A History of Immunology. San Diego, Academic Press.
- Silverstein, A. (2003). "Cellular versus humoral immunology: a century-long dispute." Nature Immunology **4**(5): 425-428.
- Simpson, N., S. Lenton and R. Randall (1995). "Parental refusal to have children immunised: extent and reasons." British Medical Journal **310**(6974): 225.
- Skea, Z., V. Entwistle, I. Watt and E. Russell (2008). "'Avoiding harm to others' considerations in relation to parental measles, mumps and rubella (MMR) vaccination discussions - An analysis of an online chat forum." Social Science & Medicine **67**(9): 1382-1390.
- Sloan, R. P., E. Bagiella and T. Powell (1999). "Religion, spirituality, and medicine." The Lancet **353**(9153): 664-667.

- Slovic, P. (1992). Perceptions of Risk: Reflections on the Psychometric Paradigm. Social Theories of Risk. S. Krimsky and D. Golding. Westport,CT, Praeger: 117-152.
- Smailbegovic, M., G. Laing and H. Bedford (2003). "Why do parents decide against immunization? The effect of health beliefs and health professionals." Child: Care, Health and Development **29**(4): 303-311.
- Smith, K. (2002). "Medical Immunology: a new journal for a new subspeciality." Medical Immunology **1**(1): editorial.
- SoH (2004). Code of Ethics and Practice. Northampton, Society of Homeopaths: 21.
- Sontag, S. (1978). Illness as Metaphor. New York, Vintage Books.
- Sporton, R. K. and S.-A. Francis (2001). "Choosing not to immunize: are parents making informed decisions?" Fam. Pract. **18**(2): 181-188.
- Stacey, M. (1988). The Sociology of Health and Healing. London, Unwin Hyman.
- Stevenson, F. and G. Scambler (2005). "The relationship between medicine and the public: the challenge of concordance." Health (London) **9**(1): 5-21.
- Stone, D. A. (1986). "The resistable rise of preventative medicine." Journal of Health Politics, Policy and Law **11**(4): 671-696.
- Straus, R. (1957). "The Nature and Status of Medical Sociology." American Sociological Review **22**(2): 200-204.
- Strauss, A. and J. Corbin (1990). Basics of Qualitative Research. Newbury Park, California, Sage.
- Strauss, A. and J. Corbin (1998). Basics of Qualitative Research : grounded theory procedures and techniques. London, Sage.
- Streefland, P., H. (2001). "Public doubts about vaccination safety and resistance against vaccination." Health Policy **55**(3): 159-172.
- Sullivan, M. (1986). "In What Sense is Contemporary Medicine Dualistic?" Culture, Medicine and Psychiatry(10): 331-350.
- Sussman, L. and W. Sussman (2004). Vaccinations - yes or no?. Bournemouth, Merrydown Publishing Co Ltd
- Tayil, S. E., El-Shazly, M.K., El-Amrawy, S.M., Ghouneim, F.M., Abou Khatwa, S.A., and Masoud, G.M. (1998). "Sero-epidemiological study of measles after 15 years of compulsory vaccination in Alexandria, Egypt " Eastern Mediterranean Health Journal **4**(3): 437-447.

- Taylor, B., E. Miller, C. Farrington, M.-C. Petropoulos, I. Favot-Mayaud, J. Li and P. A. Waight (1999). "Autism and measles, mumps, and rubella vaccine: no epidemiological evidence for a causal association." The Lancet **353**(9169): 2026-2029.
- Telford, R. and A. Rogers (2003). "What influences elderly people's decisions about whether to accept the influenza vaccination? A qualitative study." Health Education Research **18**(6): 743-753.
- ttmc. (2008). "What is the size of the Global pharma market?" Retrieved 27 October 2008, 2008.
- Turner, B. (1984). The Body and Society. Oxford, Basil Blackwell.
- Turner, B., S., Ed. (2003). The mainstreaming of complementary and alternative medicine. London, Routledge.
- van den Hof, S., J. Wallinga, M. A. Widdowson and M. A. E. Conyn-Van Spaendonck (2002). "Protecting the vaccinating population in the face of a measles epidemic: assessing the impact of adjusted vaccination schedules." Epidemiology and Infection **128**(1): 47-58.
- Vivat, B. (2006). Spirituality in the Hospice Movement. Edinburgh, Edinburgh University. **PhD**.
- Wakefield, A., S. Murch, D. Anthony, J. Linnell, D. M. Casson, M. Malik, M. Berelowitz, A. Dhillon, M. Thomson, P. Harvey, A. Valentine, E. Davies and J. Walker-Smith (1998). "Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children." Lancet **351**(Feb.): 637-652.
- Weston, A. (1992). On medical self-care and holistic medicine. Medical Thought and Practice. E. Leder. Dordrecht, Kluwer.
- WHO. (2008). "Measles in Finland 2008." data.euro.who.int Retrieved 13/01/2008, 2009.
- Wilson, R. and E. A. C. Crouch (1987). "Risk Assessments and comparisons: An Introduction." Science, Technology, & Human Values **236**: 267-270.
- Winston, J. (1999). The faces of homeopathy: a history of the first 200 years. Wellington, Great Auk Publishing.
- WMA. (1964). "Ethical Principles for Medical Research Involving Human Subjects " World medical association declaration of Helsinki. Retrieved July 26, 2008.
- Wolf, O., Ed. (1982). An Outline of a Spritual Scientific Oriented Medicine. The Anthroposophical Approach To Medicine. Spring Valley, New Yorl, The Anthroposophic Press.

- Wolfe, R. M. and L. K. Sharp (2002). "Anti-vaccinationists past and present." BMJ **2002**(325): 430-432.
- Wynne, B. (1992). Risk and Social Learning: Reification to Engagement. Social Theories of Risk. S. Krinsky and D. Golding. Westport, CT, Praeger.
- Zola, I. K. (1972). "Medicine as an institution of social control." Sociological Review(20): 287-503.

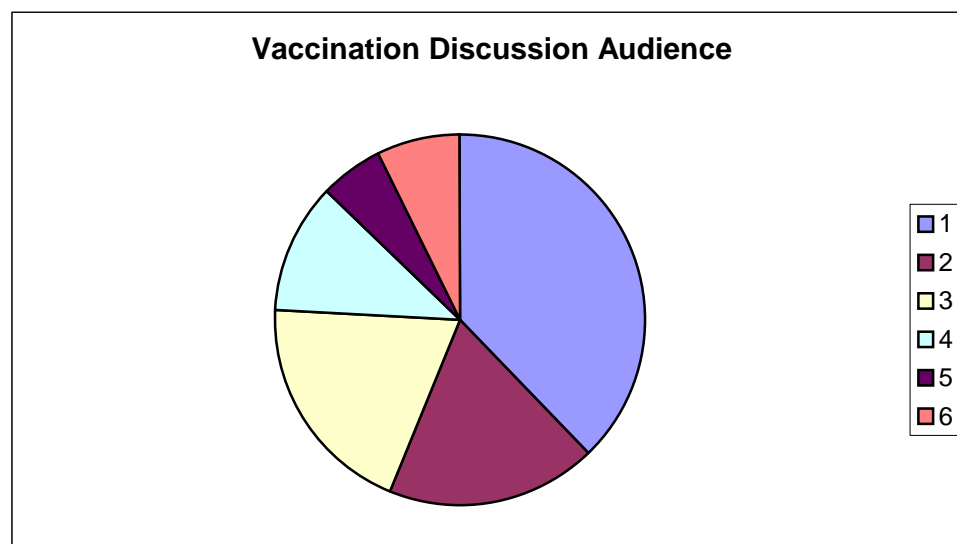
Appendix 2. Quantitative data from exploratory research.

Date	Parnt expctng 1st child	Parnt expctng 2nd/ 3rd child	Parent with baby	Health worker	Journalist	Other	Total nos.
29-Jan-97	4	1	2	0	0	1	8
24-Feb-97	2	2	3	1	0	1	9
31-Mar-97	0	1	3	1	2	0	7
28-Apr-97	2	0	2	0	1	1	6
26-May-97	3	1	2	2	0	0	8
30-Jun-97	4	2	3	0	0	0	9
29-Sep-97	3	2	4	2	2	1	14
27-Oct-97	2	1	3	0	0	0	6
31-Nov-97	5	1	1	0	0	1	8
30-Mar-98	6	2	2	0	0	0	10
27-Apr-98	2	0	0	0	0	0	2
25-May-98	4	4	1	0	1	1	11
28-Sep-98	4	2	2	6	0	0	14
26-Oct-98	4	2	4	1	1	1	13
30-Nov-98	6	2	1	1	0	0	10
22-Feb-99	2	1	0	0	0	1	4
29-Mar-99	3	2	2	0	0	0	7
31-May-99	6	0	0	0	0	0	6
28-Jun-99	2	1	0	5	1	1	10
27-Sep-99	4	2	2	0	0	1	9
29-Nov-99	3	2	2	0	2	0	9
30-Jan-00	4	3	2	1	0	1	11
28-Feb-00	8	2	0	0	0	0	10
27-Mar-00	5	4	1	2	3	1	16
29-May-00	2	0	2	1	0	1	6
25-Sep-00	4	1	4	1	0	2	12
28-Oct-00	6	0	0	2	2	1	11
27-Nov-00	2	1	2	0	0	1	6
29-Jan-01	3	0	3	0	0	0	6
26-Feb-01	6	4	4	0	2	0	16
26-Mar-01	4	6	0	3	0	1	14
30-Apr-01	1	4	0	5	0	3	13
28-May-01	0	0	4	1	0	1	6
Totals	116	56	61	35	17	22	307

The data does give some indication of the kinds of people who were interested in the discussions, what time of year people are most likely to go attend such events and it shows that it was mostly parents expecting their first child who attended these classes.

The Graph below (next page) shows the same material but is easier to see the information.

Appendix 2a. Preliminary research Graph



Explanation of Key:

1. Parent expecting their first child
2. Parent expecting 2nd or subsequent child
3. Parent with baby
4. Health worker
5. Journalist/researcher
6. Other (grandparent, member of staff or interested party)

Appendix 2 c.

Interviews not used in this research project and reason why

Respondent #	Bad recording	Talking as a doctor	Talking as a homeopath	No recording at all	Incomplete interview
16	√				
17	√				
18		√			
19			√		
20				√	
21				√	
22				√	
23				√	
24					√
25				√	
26					√
27		√			
28	√				
29					√
30			√		

Appendix 3. Research Leaflet and Consent Form

Thank you for taking the time to read this information

Should you have any more questions about the research, or if you are interested in taking part in the study, please do not hesitate to contact me by phone, e-mail or letter.

Eva Tombs-Heirman

Phone: (0131) 228-3716
E-mail: E.F.Tombs-Heirman@sms.ed.ac.uk

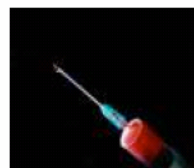
Contact Address

Room 815, Public Health Sciences
The University of Edinburgh
Medical School, Teviot Place
Edinburgh EH8 9AG

Supervisor for the research

Professor Sarah Cunningham-Burley
0131 650 3217 or 0131 651 1832
E-mail: sarah.cburley@ed.ac.uk
Room 515, Public Health Sciences,
The University of Edinburgh
Medical School, Teviot Place
Edinburgh EH8 9AG

Exploring People's Decisions not to Vaccinate



An MPhil Study

Eva Tombs-Heirman

Research Student
Community Health Sciences
University of Edinburgh

You are invited to take part in this research study. Before deciding whether or not you would like to take part, please take the time to read through this information leaflet carefully.

What is the purpose of this study?

Although the majority of people are vaccinated and have their children vaccinated, there has always been a minority who make a different choice in deciding not to do so. Recent controversies have brought the issue of vaccination to the public's and health services' attention once more. This interview study will look at the range of reasons why people decide not to have their child or themselves vaccinated in order to find out more about people's views and experiences of health, illness and medical interventions.

Who can take part in the research?

People, aged over 18 years, who take the responsibility for deciding whether to have their child vaccinated or themselves can take part in the research.

What can I expect to happen if I decide to take part?

You will be asked to sign a consent form confirming that you wish to take part. You will be given a copy of this leaflet and a consent form to keep. Even after signing the consent form, you can withdraw from the interview study at any time and without having to give a reason.

The interview may take about one hour. It will be quite informal and will take place at a time and a place of your choice. Interviews will be recorded (if you agree to this) and will then be listened to and transcribed/typed by me.

In the interview you will have the opportunity to discuss your ideas on health and vaccinations and how you came to make the decisions about not having the jabs. You may also want to discuss how others' viewed your decision and how you feel now about decisions you made in the past.

Are there any benefits to taking part?

There will be no benefit to you from taking part although it is hoped that you will enjoy talking about your thoughts and experiences in a relaxed atmosphere.

Will everything I say be kept confidential?

All names used - yours, your child's and anyone you talk about - will be changed in the thesis and other publications relating to the study. No personal information will be given or made available to anyone else.

What will happen to the interview tapes and transcripts?

The recordings of the interviews will be stored securely and only listened to by myself. Excerpts from the transcribed interviews will only appear in print form with names changed and other personal identifiers removed. The supervisor for the MPhil is Sarah Cunningham-Burley (University of Edinburgh) may read parts of the transcripts. You can request a copy of your own transcript if you wish.

Appendix 3a. Consent form

Consent Form

**Title of Study: Exploring People's Decisions
not to Vaccinate**

I understand that taking part in this study will involve being interviewed by
a trained researcher as part of her postgraduate studies. ☐

I understand that all information is confidential and no names will be used
in the thesis, reports or publications. ☐

I understand that I can withdraw from the study at any time without giving
a reason. ☐

I agree to the interview being audio-recorded. ☐

I have read and understood the information leaflet and have had the
opportunity to ask questions about the research. ☐

I would like to take part in the study. ☐

Signed: _____ Date: _____

Name (please print): _____

Signature of researcher _____
Eva Tombs-Heirman

Appendix 4. Code of Ethics and Checklist.

University of Edinburgh

Public Health Sciences

POSTGRADUATE RESEARCH ETHICS REVIEW FORM

This form should be completed for every postgraduate student research project involving human participants. Its use is intended to foster good ethical standards of research practice in postgraduate students within this Public Health Sciences. Before completing this form, please refer to PHS's Code of Practice on Ethical Standards for Social Research Involving Human Participants. If the student's project involves only secondary data analysis, the supervisor will nevertheless be required to sign off the form.

The student's supervisor is responsible for exercising appropriate professional judgement on the information given and should complete **Section III** of this form.

Students should retain a copy of the form and submit it with their dissertation (bound in as an appendix). Please note that it is your responsibility to follow PHS's Code of Practice on Ethical Standards and any other relevant academic or professional guidelines in the conduct of your study. This includes providing appropriate information sheets and consent forms, copies of which should be submitted with your dissertation, and ensuring confidentiality in the storage and use of data.

This checklist must be completed before potential participants are approached to take part in any research.

Section 1: Postgraduate Student Details

1. Student's name	Eva Tombs-Heirman
2. Email address	E.F.Tombs-Heirman@sms.ed.ac.uk
3. Course name	MPhil
4. Supervisor's name	Prof Sarah Cunningham-Burley
5. Email address	Sarah.C.Burley@ed.ac.uk

Section II: Research Project Details

6. Project Title	Understanding vaccination refusal
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Section III: For Supervisor completion (please tick boxes)

The student confirms reading the Division's Code of Practice	Y
The topic merits further research	Y
The participant information sheet or leaflet is appropriate or not required (please specify)	Y
The procedures for recruitment and obtaining informed consent are appropriate or not required (please specify)	Y

Section IV: Preliminary Checklist (please tick boxes)

	YES	NO
1. Does the study involve participants who are particularly vulnerable or unable to give informed consent? (e.g. young children, people with severe learning disabilities, your own patients or employees)		X
2. Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group, residents of nursing homes)		X
3. Will it be necessary for participants to take part in the study without their knowledge/consent at the time? (e.g. covert observation of people)		X

in non-public places)		
4. Will the study involve discussion of topics which the participants may find sensitive? (e.g. sexual activity, personal drug use)		X
5. Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants?		X
6. Will the study involve invasive, intrusive or potentially harmful procedures of any kind?		X
7. Will blood or tissue samples be obtained from participants?		X
8. Is pain or more than mild discomfort likely to result from the study?		X
9. Could the study induce psychological distress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?		X
10. Will the study involve prolonged or repetitive testing?		X
11. Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?		X
12. Will the study involve recruitment of patients or staff through the NHS?		X

If you answered 'yes' to any of the questions in **Section IV**, you will need to describe how you plan to deal with the ethical issues raised by your research in **Question 18** below. If you answered 'yes' to **Question 12**, you must also submit an application to the appropriate external health board ethics committee.

Section V: Summary of Proposed Research

13. Background and rationale for study

18. Potential adverse effects and steps to be taken to deal with them (Outline any invasive procedures, potential psychological distress, anxiety or upset, or any harm or negative consequences which may be induced by the study, and the steps to be taken to address them. These should relate to the questions you have answered 'yes' to in Section IV)
NONE
19. Potential benefits of proposed research (Outline the potential benefits of the research for science and/or society)
<p>To further understanding of lay health beliefs and practices in the context of non-vaccinating parents</p> <p>To facilitate understanding between complementary and biomedical practices</p>
20. Steps to be taken to ensure confidentiality of data (Outline steps to ensure confidentiality, privacy and anonymity of data during collection, storage and publication)
<p>Recordings of data kept in password protected PC and locked filing cabinets. Transcripts also kept in password protected PC and locked filing cabinets. Real names are not used. Any personal data held only for duration of study for contact purposes and held separately from interview data and again in secure conditions.</p>

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Section VI: Funding

21. Please indicate source of research funding:	
	Internal Department/University funds (please indicate source)
	External funds (please indicate source)
Y	As part of degree/training or 'own account' research for MPhil, self funded.

Signed: Postgraduate Student

Signed: *Sevan Wainwright-Burley* Supervisor

Date: ...31st October 2008

Appendix 5. Topic Guide

My topic guide did change as I became more experienced with interviewing. I had developed several pages of questions based on what I had heard in the focus groups. These were soon abandoned after I found that I wasn't sticking to them even during the preliminary research, and peoples' own stories were more interesting and varied and closer to what actually happened in their lives than answers to someone else's (mine in this case) questions.

I did retain some guidelines in the form of prompting questions, to use incase things didn't happen in an interview.

Prompting Questions

I often started with:

"Can you tell me something about your experiences"....

Or **"Can you tell me the story behind your experience"....:**

- 1) of vaccinations
 - (a) for yourself?
 - (b) for your child?
 - (c) for your partner?
 - (d) with other people?
- 2) of how you made that decision?
- 3) of who or what influenced you?
 - (a) what happened?
- 3) of how it has affected your relationships with:
 - (a) your family and friends?
 - (b) medical professionals?
 - (c) schools, nursery or playgroup?
- 4) of how it has affected your child?
 - (a) what happened?
- 5) about how you look after the health of your child?
 - (a) when they are ill?
- 6) of how you think about world health, the health of others?

If the above questions didn't seem appropriate or the flow became difficult, or there was an interruption and I found it necessary to make a prompting question or remark or I found that asking:

"What did you think about that?" or "How did that make you feel?" or "What happened then?"...would often be suitable to get the person going again.

